

**“A BALANCING ACT”: AN INTERPRETIVE DESCRIPTIVE STUDY OF PARENTS’
EXPERIENCES RAISING A CHILD WITH ASPERGER’S SYNDROME**

by

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ABSTRACT

This thesis is an interpretive description of parents' experiences raising a child, 11 to 19 years, with Asperger's Syndrome (AS). Eight families consisting of 13 parents (8 mothers and 5 fathers) participated. Data collection comprised of semi-structured interviews with parents, demographic information for each parent, and field notes. The analytic method of constant comparison (Thorne, 2008), informed by grounded theory methodology (Glaser & Strauss, 1967), allowed for the identification of commonalities across parents' experiences. The core concept of a 'balancing act' was identified, which was comprised of three key themes: "losing our footing," "regaining our balance" and "helping others find their balance." The findings shed light on how parenting a child with AS is a complex and evolving process in which parents struggle to find the right balance for themselves, their child with AS, and their family as a whole. Over time, parents gain knowledge and skills related to the AS, how to read their child and the AS, and effective strategies to manage the AS in the context of family life. This balancing act is often witnessed and judged by an audience of others (i.e., school and health professionals, extended family, and strangers), which can compromise parents' ability to find and maintain balance. Findings from this study have application potential to practice, education, and research domains, helping to raise awareness of what it is like to parent a child with AS and inform and strengthen the care provided to families experiencing AS.

PREFACE

Ethical approval was obtained for the purposes of this study from The University of British Columbia Okanagan Behavioural Research Ethics Board. The Certificate Number of the Ethics Certificate obtained was H09-01376.

TABLE OF CONTENTS

ABSTRACT	ii
PREFACE	iii
TABLE OF CONTENTS	iv
LIST OF TABLES	ix
ACKNOWLEDGEMENTS	x
DEDICATION	xii
CHAPTER ONE: INTRODUCTION	1
Background to the Problem.....	1
Problem Statement	2
Purpose	2
Research Question.....	3
Theoretical Framework	3
Assumptions	5
Definition of Terms	5
Autism Spectrum Conditions (ASCs).....	5
Asperger’s Syndrome (AS).....	6
Family	6
Parent	7
Thesis Organization.....	7
CHAPTER TWO: LITERATURE REVIEW	8
The Asperger’s Profile	8
Asperger’s in Girls.....	12

Autism and Asperger’s Syndrome Through an Historical Lens	14
Putting Asperger’s on the Map	18
Parenting Experiences	19
Obtaining the Diagnosis of Asperger’s Syndrome	19
Impact of a Delayed Diagnosis	21
Parental Reactions to the Diagnosis.....	22
Parental Stress and Asperger’s Syndrome.....	23
Significance of Study	29
Summary	30
CHAPTER THREE: RESEARCH METHOD.....	31
Theoretical Underpinnings	31
Selection Criteria for the Participants	32
Inclusion Criteria	32
Exclusion Criteria	32
Recruitment Process.....	33
Description of Participants	34
Data Collection.....	36
Data Analysis	38
Ethical Considerations.....	40
Locating the Self	42
Credibility and Rigour.....	45
Limitations of the Study.....	48
Summary	49

CHAPTER FOUR: FINDINGS	50
Losing Our Footing.....	50
Noticing Differences.....	50
Running into Problems	55
Searching for Answers.....	59
Encountering parental blame.....	60
Seeking professional help.....	65
Unhelpful answers from school professionals	65
Unhelpful answers from health care professionals	70
Persevering Through the Problems.....	77
Crisis Points	79
Regaining Our Balance	82
Finally Finding a Name	82
Becoming Experts on their Child and the AS.....	87
Separating the child from the AS	87
Adjusting expectations	89
Managing emotions.....	96
Balancing teaching and letting go	98
Balancing structure and flexibility	100
Balancing maintaining dependence and encouraging independence	102
Balancing parental roles and responsibilities	105
Helping Others Find Their Balance	109
Advice for Parents	109

Advocating for help.....	109
Becoming informed.....	110
Appreciating your child.....	111
Reaching out to others.....	112
Advice for Health Care Professionals.....	113
Early identification and intervention.....	113
Tailoring services and supports.....	115
Respite.....	117
Summary.....	118
CHAPTER FIVE: DISCUSSION, IMPLICATIONS, AND CONCLUSIONS.....	120
Synopsis of Findings.....	120
Confirming and Extending What is Known.....	122
Blame and Stigma.....	122
Strength and Resiliency.....	124
Identifying Positive Experiences.....	124
Parenting as A Process.....	126
Identifying with their Child.....	126
Constructing Their Own ‘Normal’.....	127
Persistent Experiences of Unhelpful Help.....	128
Cost to Family Integrity.....	129
Aggressive and Self-Harm Behaviour.....	130
Implications for Practice.....	131
Implications for Education.....	132

Implications for Research.....	134
Conclusion.....	137
REFERENCES.....	139
APPENDICES.....	149
APPENDIX I: DSM-IV Diagnostic Criteria for AS.....	149
APPENDIX II: Sampling Criteria.....	151
APPENDIX III: Letter of Introduction and Invitation to Participate in Study.....	152
APPENDIX IV: Consent to Contact Form.....	153
APPENDIX V: Advertisement.....	155
APPENDIX VI: Draft Interview Guide.....	156
APPENDIX VII: Demographic Form.....	158
APPENDIX VIII: Sample Format for Recording Fieldnotes.....	160
APPENDIX IX: Informed Consent Form.....	161
APPENDIX X: Supports for Parents of Children with AS.....	164

LIST OF TABLES

Table 1.	Parent demographics	35
Table 2.	Child demographics	35
Table 3.	Data collection	37

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DEDICATION

I would like to dedicate this work to all families experiencing AS, including my own. It is my hope that you find this work informative and helpful, serving as guidance and support in your own journeys through AS.

CHAPTER ONE: INTRODUCTION

The following document pertains to a qualitative research project on parents' experiences raising a child with Asperger's Syndrome. The introduction will set the stage for the ensuing chapters of the thesis, laying the foundation for understanding the topics discussed.

Background to the Problem

What is the nature of parents' experiences raising a child with Asperger's Syndrome? This is the fundamental question underpinning my thesis study, and one that warrants further attention.

Asperger's Syndrome (AS), a high functioning form of autism, is increasing in prevalence. The number of paediatric cases with an autism spectrum condition (ASC), including AS, is exponentially climbing. While definitive data regarding the specific prevalence of AS are lacking (American Psychiatric Association [APA], 1994), within Canada it is estimated that one in 165 children has an ASC (Fombonne, Zakarian, Bennett, Meng & McLean-Heywood, 2006). Within the U.S., it is estimated that one in every 110 children is diagnosed with an ASC (Centers for Disease Control and Prevention, 2007). In the largest epidemiological study of ASCs to date, conducted in England, the estimated prevalence of ASCs is 116/10,000, or approximately 1% of the paediatric population (Baird et al., 2006). This is a significant increase from earlier estimates that indicated prevalence to be quite rare with ASCs occurring in 4.5 per 10,000 children (Lotter, 1966). The prevalence rates have increased 10 fold over the past decade, leading to the question of why such a dramatic increase has occurred (VanBergeijk & Shtayermman, 2005). Likely explanations include greater awareness of ASC symptoms, and the inclusion of broader criteria for the diagnosis of ASCs (Muhle, Trentacoste, & Rapin, 2004), although a definitive reason for such a massive increase in prevalence remains unknown. Above all, children are being diagnosed

with ASCs at a greater rate than ever before. As the prevalence rate continues to dramatically rise, ASCs are gaining recognition as an emerging public health concern.

Problem Statement

Despite the rising prevalence rate, little is understood of parents' experiences raising a child with AS. There has been an increasing trend to focus on the causes and specific sequelae of social deficits in AS with a comparative lack of research on parents' experiences (Blacher, Kraemer, & Schalow, 2003). The family studies in the autism literature tend to meld AS with other autism spectrum conditions (Huws, Jones, & Ingledew, 2001; Schall, 2000) or with co-morbid conditions such as learning disability (Benderix, Nordstrom, & Sivberg, 2006; Little & Clark, 2006), limiting insight into parents' experiences raising a child with AS. A select number of studies have recently begun to recognize this key gap in the literature, shedding some light on parents' experiences raising a child with AS, and the potential this knowledge holds to inform service provision and policy development into the future (Brewin, Renwick, & Schormans, 2008; Chell, 2006; Lasser & Corley, 2008; Portway & Johnson, 2003). However, these studies privilege mothers' perspectives raising male children with AS, and do not provide insight into parenting from the perspectives of both mothers and fathers of male and female children. As the number of children with ASCs continues to rise, more parents will be in need of services and supports. Thus, it is vitally essential to shine the research spotlight on mothers' and fathers' experiences raising male and female children with AS to deepen understanding of parents' needs, strengthen the delivery of services and supports, and enhance parents' ability to manage AS.

Purpose

The purpose of this study was to describe and interpret what parents experience in raising a child with AS. In describing and interpreting parents' experiences, my goal was to increase

awareness and deepen understanding of what is most relevant and salient to parents in raising a child with AS. Through the analysis of the data, the key themes were identified and organized in a way that sheds new light on parents' experiences. The findings hold the potential to inform the delivery of healthcare to families raising children with AS, strengthening the services and supports provided to this population. Further, the findings may be utilized by families raising children with AS who are interested in learning from other families, receiving vicarious support and validation from those who have walked a similar path.

Research Question

In my quest to understand what parents experience in raising a child with AS, the following research question was formulated: What is the nature of parents' experiences raising a child with AS?

Theoretical Framework

The theoretical perspectives of social constructivism and family systems theory helped shape this study. This section will review these two theoretical perspectives, and examine how they informed this study.

Social constructivism is a paradigm, or worldview, which puts forth that individuals seek to understand the world in which they live and work, and develop subjective meanings of their experiences (Creswell, 2007). Researchers drawing upon social constructivism believe in multiple, subjective realities, the co-construction of knowledge between researcher and respondent, and understanding a phenomenon within the natural setting from the perspective of those experiencing it (Denzin & Lincoln, 2005). Social constructivism underpinned my assumption that parents construct their knowledge based on experiences and perspectives, and therefore I needed to explore these experiences and perspectives to uncover a deep level of

knowledge on the topic of interest. Repeated, semi-structured interviews were conducted with parents in a natural setting of their choice, utilizing open-ended questions to elicit the most relevant and salient aspects of their experiences. Further, my understanding and interpretation of parents' experiences was co-constructed with participants through dialogic interaction in the context of the interview (Constantino, 2008). To demonstrate this co-construction of knowledge, I remained true to participants' voices by incorporating quotes within the findings chapter (see CHAPTER FOUR) to support the interpretations made. Further, I recognized that my own personal and disciplinary background shaped how I interpreted parents' experiences of raising a child with AS, and therefore in the methodology chapter (see CHAPTER THREE) I have positioned or "located" myself in the research. Overall, social constructivism provided a theoretical perspective congruent with the approach taken to researching the phenomenon of parenting a child with AS.

In addition to social constructivism, family systems theory (Wright & Leahey, 2009) informed this study. One of the central tenets of family systems theory is that a change in one family member affects all family members (Wright & Leahey). Thus, a significant change such as having a family member diagnosed with AS will affect all family members to varying degrees. As parents are the ones who determine how the family responds to and manages a diagnosis of AS, this study involved interviewing parents to understand their experiences of raising a child with AS. Mothers and fathers were included in the research process to explore how they are each impacted by raising a child with AS. Family systems theory recognizes that parents are not only the primary support systems for their child but also legitimate recipients of concern and care. Thus, family systems theory supported my concern for parents and the importance of including both mothers and fathers in this research.

Assumptions

In addition to the theoretical assumptions noted above, the following assumptions were made in reference to this study:

- 1) Parents of children with AS who agreed to participate in this study did so willingly, and were genuinely interested in sharing their experiences of raising a child with AS.
- 2) Parents of children with AS shared what was most relevant and salient to their experiences.
- 3) Knowing their child's diagnosis for a minimum of two years provides parents with a sufficient amount of time to adjust to the diagnosis and develop expertise in managing their child with AS.

Definition of Terms

It is important to clarify the definitions for several terms used within this thesis.

Autism Spectrum Conditions (ASCs)

ASCs refer to a group of conditions on the autism spectrum, ranging from mild to severe. ASCs are synonymous with the broad category of Pervasive Developmental Disorders described in the Diagnostic and Statistical Manual of Mental Disorders, fourth edition (APA, 1994), also referred to as the DSM-IV, and the International Classification of Diseases, 10th revision (WHO, 1992), also referred to as the ICD-10. The use of the term 'spectrum' suggests the dimensional nature of autism while 'condition' refers to a different way of being in and perceiving the world. As there is no universal agreement on the correct terminology when discussing autism, the use of 'disorder' may be used as well as 'condition' (Roth, 2010). The term 'disorder' has long been used in the clinical realm where a diagnosis is given and treatment is prescribed (Roth). The neutral term 'condition' has gained prominence over the past decade as

some individuals on the spectrum, and their families, have rejected the implication that they have a disorder (Roth). However, this is not to palliate the seriousness of autism but to call attention to different ways of looking at autism through a lens that acknowledges the challenges as well as the strengths, a lens that does not limit the potential of the individual based on his/her diagnosis. Thus, the use of ‘condition’ will be used in reference to the autism spectrum as it is a more neutral term that abstains from the pathological implications and pejorative associations of ‘disorder’ (Baron-Cohen, 2002; Baron-Cohen et al., 2009).

Asperger’s Syndrome (AS)

AS is a high-functioning form of autism characterized by impairments in social functioning, and restricted, repetitive, and stereotyped patterns of behaviour, interests, and activities (APA, 1994). There are no clinically significant delays in language or cognitive development (APA). There is growing evidence that ASCs, including AS, are neurobiological conditions (Akshoomoff, Pierce, Courchesne, 2002; DiCicco-Bloom et al., 2006; Volkmar, Klin, Schultz, & Cohen, 1998) with strong heritability (Baron-Cohen, 2004; Muhle, Trentacoste, & Rapin, 2004; Rutter, 2005). However, the specific etiology remains unknown (Akshoomoff et al., 2002; DiCicco-Bloom et al., 2006; Muhle et al., 2004). AS is defined using the criteria set forth by the Diagnostic and Statistical Manual of Mental Disorders, fourth edition (APA), also referred to as the DSM-IV (see Appendix I for DSM-IV Diagnostic Criteria for AS). For the purposes of this study, families must have received a clinical diagnosis of AS by a qualified health professional (e.g., paediatrician, psychiatrist, or registered psychologist).

Family

Family is defined according to Wright and Leahey (2009) who believe that “the family is who they say they are” (p. 50). This definition challenges the boundaries that confine family to a

group of individuals who are linked by blood, adoption, or marriage. Rather, family is comprised of individuals who are bound by “strong emotional ties, a sense of belonging, and a passion for being involved in one another’s lives” (Wright & Leahey, p. 50).

Parent

Parent is defined as “a father or mother; one who begets or one who gives birth to or nurtures and raises a child; a relative who plays the role of guardian” (Princeton University, 2009). The following family types were eligible to participate in the study: single parent, dual parent, blended, same sex, grandparent headed, and/or adoptive families. The recruitment of participants yielded dual parent families.

Thesis Organization

This research study is presented in six chapters. CHAPTER ONE is an introduction that lays the foundation for the rationale of this study, including a discussion of the background to the problem, problem statement, and purpose, and a delineation of the research question, theoretical framework, assumptions, and a definition of key terms. CHAPTER TWO presents a review of the literature on parenting a child with AS, teasing out the key gaps and supporting the importance and relevance of this work. CHAPTER THREE presents the research method, exploring the procedures of data collection and analysis, and addressing credibility, rigour, and ethical considerations. CHAPTER FOUR offers a thorough account of the findings. CHAPTER FIVE discusses the findings in the context of the current literature, and brings the report to a close with implications for future practice, education, and research and conclusions.

CHAPTER TWO: LITERATURE REVIEW

As the prevalence of AS continues to rise, more families of children with AS will be in need of services and supports to address their needs and enhance their ability to manage AS. Moreover, as the literature on parenting a child with AS continues to be exploratory and contains numerous gaps, there is a critical need for more research in this area. This chapter will present a review of the literature: 1) differentiating AS from classic autism and exploring its symptomatology within the three core domains of social, communicative, and behavioural functioning; 2) situating AS within an historical context to showcase how it was first described in detail and how our understanding of children with AS and their parents has evolved over time; and 3) discussing parenting experiences in the context of the current literature on AS, illuminating the key gaps and lending support for the importance and relevance of this study.

The Asperger's Profile

ASCs are diagnosed when abnormalities are present in a “triad” of behavioural domains, specifically social development, communication, and repetitive behaviour and narrow interests (Muhle, Trentacoste & Rapin, 2004). Although these three key areas of atypical development are implicated in ASCs, Baron-Cohen (2008) believes that one cannot separate the social and communication domains, as communication is essentially social in nature. As a result, it may be more fruitful to conceptualize the diagnostic features of ASCs in two broad areas: social communication and narrow interests/repetitive actions (Baron-Cohen, 2008). Although AS and classic autism share features in these two broad areas, they are defined as different by their history of language and cognitive development. AS is different from classic autism as there is no history of language delay, and the Intelligence Quotient is in the average to above average range (Baron-Cohen, 2004; Baron-Cohen et al., 2005; Marshall, 2002). In classic autism, there is a

history of language delay and IQ can be anywhere on the scale (Baron-Cohen, 2008). As a result, AS is classified as a high-functioning form of autism, whereas classic autism is considered to be on the more severe or 'low functioning' end of the spectrum.

Classifying AS as a high-functioning form of autism has often led others to claim it is a 'mild' condition, minimizing or even denying the challenges that do exist. Further, the AS diagnosis is often given in late childhood, adolescence or even adulthood, further compounding the belief that this condition is "mild" and can be overlooked early in the child's development (Frith, 2003). The epithet of 'mild' in relation to AS has been problematized by researchers as they uncover and explore the significant challenges associated with this complex condition (Cashin, 2008; Frith, 2003). The very classification of the autism spectrum as mild, moderate, or severe is problematic because at any one time the individual with autism may slide down the continuum of impairment and experience severe challenges (Cashin, 2008). This may be observed when the child with AS who has cognitive and behavioural inflexibility has a temper tantrum when exposed to change, exhibiting regression in behavioural functioning (Cashin). Further, the effects of AS become more obvious with the child's increasing age, and individuals with AS may experience intolerable difficulties, particularly in the area of social communication (Frith, 2003). Thus, it is vitally essential to challenge the assumption that AS is a mild condition, increasing awareness of the full profile of AS, including its impact on the individuals affected and their families.

As an essential feature of their difference, individuals with AS experience social difficulties, in addition to narrow interests, repetitive routines, speech and language peculiarities, nonverbal communication difficulties, and motor clumsiness (Weber, 2008). The social deficits are a source of considerable disability, and may include difficulty initiating and maintaining

conversation, impaired ability to intuit the non-verbal cues in social interaction and respond appropriately, and lack of social and emotional reciprocity (APA, 1994). This lack of social understanding can result in social isolation, and may increase the child's risk of being bullied and teased.

Children with AS are at high risk of depression and poor long-term mental health outcomes because of their social isolation, inflexible thought processes, and limited psychological coping mechanisms (Portway & Johnson, 2003). As children with AS transition into adolescence, their perception of being different from others may lead to significant problems with self-esteem, and symptoms of anxiety and depression may arise (Myles & Simpson, 2002; Tantam & Prestwood, 1999). In fact, an additional mood disorder may be the "rule rather than the exception" in teenagers with AS (Attwood, 2007). According to Attwood (1998), the most common cause of depression for this population is striving to have friends but not succeeding in developing and maintaining friendships. Children with AS want to have friends but are puzzled about how to achieve this aim, and they can become easily frustrated as adolescence ensues and the social world becomes increasingly complex. As children with AS experience numerous unsuccessful attempts at friendship they may give up trying to interact with others and isolate themselves, further compounding their awkward and eccentric social behaviour (Ozonoff, Dawson, & McPartland, 2002).

In addition to social impairments, children with AS usually have communication problems. Although children with AS exhibit no delays in the development of language and often present as verbally fluent, there are significant problems with pragmatics, or the social use of language. According to Landa (2000), pragmatic impairment may be the most stigmatizing and handicapping aspect of AS. Children with AS often exhibit pedantic speech in which they

are overtly formal and speak as the expert source of knowledge on their specific interest, leading to the colloquial term “little professors” to be ascribed to these children. Ozonoff et al. (2002) described one young boy who, at the age of 7, amassed a large vocabulary and began many statements as though a professor might, saying “Actually...” or “I do believe...” (p.13), making him stand out from his peers as different, and become the target of teasing. In social interaction, children with AS may dominate the conversation with a monologue on their specific interest, speaking at length on the factual information they have accrued in a one-sided manner without considering the needs or interests of the other person. Their speech may be too loud or too soft to be heard well, words may be spoken in a hurried or stilted manner, and there may be an unusual rhythm to their speech, with emphasis placed on the wrong words in sentences or no emphasis at all (Ozonoff et al., 2002). In addition, children with AS may initiate conversation in a socially inappropriate way (e.g., asking a stranger his or her age), and messages may be expressed in a blunt, overly direct way (Landa, 2000). Another communication problem is literal interpretation leading to difficulty understanding figurative and metaphorical language (McPartland & Klin, 2006). For example, children with AS may literally interpret sarcastic remarks without reading the underlying message.

In addition to social and communicative impairments, children with AS have impairments in the behavioural domain. A hallmark of AS is the development of a specific interest, which is circumscribed and intense (McPartland & Klin, 2006). The special interests of children with AS are diverse, and may include such subjects as geology, astronomy, mechanics, numbers, and fabrics (Myles & Simpson, 2002). These interests are often related to systems such as the motion of the planets (astronomy) or the weather (meteorology), which are governed by predictable rules and laws (Lyons & Fitzgerald, 2005). The predictability of these special

interests can provide a sense of control over the environment and may be soothing for the child with AS, reducing anxiety and helping him/her make sense of the world (Lyons & Fitzgerald). These special interests may change over time with one interest being replaced by another or they may be long-lasting, persisting into adulthood and even forming the basis of a career (Bauer, 2007). Thus, while deeply preoccupying, the interest is not deemed a clinical obsession (i.e., Obsessive Compulsive Disorder) because it is enjoyable, brings pleasure, and may ladder into a career whereas a clinical obsession is distressing and unpleasant (Attwood, 2007).

The child with AS may also exhibit inflexible adherence to routines and rituals, which are imposed on the self and/or on others (Bauer, 2007). The child, for example, may insist on a particular routine being followed prior to going to bed, or engage in a ritual in which all objects need to be lined up or symmetrical (Attwood, 2007). As with their special interests, adherence to routines and rituals can help bring order into the child's life, providing a soothing dose of reassurance that everything is predictable. When agitated, the child with AS may exhibit repetitive motor mannerisms such as gently rocking back and forth that is soothing and provides a means of relaxation (Attwood). The child may also exhibit hand or finger flapping when excited, or a motor tic that could signal a dual diagnosis of Tourette's syndrome (Attwood). The complex behavioural profile of the child with AS may contribute to the frustration of caregivers who search for ways to manage the inflexible, and often inexplicable behaviours of their child.

Asperger's in Girls

It has been well documented that ASCs are more prevalent in males than in females, with a ratio of 4 males diagnosed to every 1 female commonly reported (Schnur, 2005). In the realm of AS, the male-female ratio is estimated to be much higher with clinical observation revealing 10 males diagnosed to every 1 female (Attwood, 1998; Baron-Cohen, 2004). As there

continues to be a lack of empirical research on the sex ratio of individuals with AS, the current estimate is anecdotal, rooted in pattern observations from clinical practice (Nichols, Moravcik, & Tetenbaum, 2009). The observation that AS occurs largely in males was first noted by Dr. Hans Asperger (after whom 'Asperger's Syndrome' was coined) in 1944 who described the condition as an "extreme variant of male intelligence" (Asperger, as cited in Frith, 1991, p.84). Asperger described the typical sex differences in intelligence, noting how girls are "more gifted for the concrete and the practical, and for tidy, methodical work" and boys have "a gift for logical ability, abstraction, precise thinking and formulating, and for independent scientific investigation" (as cited in Frith, 1991, p.85). He theorized that as individuals with the condition often display such a strong preference for the logical and abstract that they neglect to form relationships with others, the condition could represent the male pattern "exaggerated to the extreme" (as cited in Frith, 1991, p.85). Although he did not encounter a female with the full profile of the condition, Asperger never discounted the possibility that females could be diagnosed with the condition.

As autism research progressed, it was noted that girls may be under-diagnosed, missed, or may express their AS symptoms differently than boys (Nichols, Moravcik, & Tetenbaum, 2009). In their book "Girls Growing Up On The Autism Spectrum," Nichols et al. (2009) note the pervasive lack of understanding in the clinical realm around girls with ASCs, including AS, with many unknowns surrounding what hinders girls from being diagnosed early and treated. Attwood (2007) has noted that girls with AS tend to be better at camouflaging their symptoms than boys, observing other girls from the sidelines, and then participating by imitating what is observed. Further, girls with AS are more likely than boys to develop a close friendship with someone who takes a liking to the "socially naïve but 'safe' girl" (Attwood, 2007, p.47). As a result, girls with

AS are less conspicuous than boys, and can fall under the diagnostic radar, receiving a diagnosis later than males with AS (Goin-Kochel, Mackintosh & Meyers, 2006). Further, the special interests of girls with AS may not be as idiosyncratic or eccentric as boys with AS. Rather, the problem may lie in the intensity and dominance of the interest in daily life (Attwood, 1998). Attwood provides the example of a girl whose special interest was horses, which, at first glance, did not appear unusual until later discovering the girl had moved her mattress into the stable so that she could sleep next to the horse. Although the anecdotal evidence abounds on how females with AS differ from their male counterparts, there continues to be a lack of solid empirical evidence on the full extent of these differences and why they occur (Nichols et al., 2009). Further, the diagnostic criteria for AS continues to avoid any mention of sex differences, increasing the difficulty faced by professionals in understanding the AS profile in girls and being able to detect and diagnose it early in the female population.

Autism and Asperger's Syndrome Through an Historical Lens

AS was first described in astute detail by Hans Asperger, a Viennese paediatrician, in 1944, when he encountered a group of boys referred to his clinic who shared a unique set of personality traits and behaviours that did not fit into any diagnostic category (Attwood, 2007). Asperger titled his pioneering paper "Autistic psychopathy in childhood," with autistic referring to the child's egocentric way of being and preference for alone time (derived from the Greek word 'autos' meaning self (Wing, 1997)), and psychopathy referring to a variant in personality (Frith, 2003). In his seminal paper, Asperger gave a detailed account of four boys, between 6 and 11 years, who presented as different from their same age peers. These boys were noted to have a striking limitation in their social relationships, lacking interest in others and failing to show the "lively reciprocity of normal social interaction" (Asperger, as cited in Frith, 1991, p.45).

Asperger described these children as “little professors” because of their circumscribed interests and pedantic speech (McPartland & Klin, 2006). The characteristic symptoms were noted to be present from the second year of life, and persisted over time; however, the symptoms were noted to often improve in adulthood with some degree of adaptation and social integration achieved (Asperger, as cited in Frith).

Around the same time, Dr. Leo Kanner, a child psychiatrist from John Hopkins Hospital in Baltimore, Maryland, was conducting work on a group of children with a unique syndrome he called “autistic disturbances of affective contact.” Kanner, unbeknownst to Asperger at the time, published his seminal paper in 1943 to English speaking communities, and received widespread attention. He gave a detailed account of 11 children, 8 boys and 3 girls, who all exhibited an “extreme autistic aloneness” that was the central feature of their condition, dominating their behaviour and interfering with their ability to navigate the social world. These children were inflexible in their need for sameness, exhibited repetitive and obsessive behaviours (e.g., repeatedly flicking light switches), had specific rituals that had to be completed by themselves or by others, failed to use language for communication, and were captivated by objects, preferring to play with them rather than with people. The children showed no interest in others and appeared to live in a world of their own. These children were considerably more impaired in their cognitive and language development than the children studied by Asperger, and would be diagnosed today as having ‘classic autism,’ which is considered to be on the low functioning end of the spectrum.

In addition to articulating the peculiar profiles of the children, Kanner gave meticulous attention to describing the parents in their “phenomenologic uniqueness” (Kanner, as cited in Rimland, 1964, p.v), sharing his impressions of their personality characteristics. He noted that all

parents were particularly obsessive and few were warmhearted, and he questioned the impact of these personality traits on the children's condition (Kanner, 1943). However, he countered this by acknowledging that the children's exquisite loneliness was present from the beginning of life, concluding that these children have come into the world without the innate ability "to form the usual, biologically provided affective contact with people" (Kanner, p.250). Although Kanner favoured the dual role of nature and nurture in producing infantile autism, others were drawn largely to his descriptions of parents as being 'cold' and their children as "kept neatly in refrigerators which did not defrost" (Kanner, 1949, p.425), giving rise to the term 'refrigerator mother.'

The propensity for parental blame was predominant at the time (mid to late 1940s) due to the continuing influence of Freudian psychoanalytic theories. Interestingly, although Asperger published his articulate and insightful case studies at the height of psychoanalytic thinking, his writing did not reveal any notion of parental blame. Unfortunately, Asperger's seminal paper was not received by a large audience as it was published during World War II, and was only accessible to the German reader (Frith, 1991). As a result, Kanner's pioneering study became the baseline for understanding and diagnosing autism, and his descriptions of parental personality characteristics offered up compelling evidence for parental pathology as a possible etiologic factor in autism (Wing, 1997).

As psychoanalytic theories of autism continued to prevail, Bruno Bettelheim, a Chicago-based psychoanalyst, rose to the fore and perpetuated this mode of thought in his research and writing. Bettelheim (1972) supported the term 'refrigerator mother,' and claimed that children became 'autistic' in response to having emotionally cold mothers who withdrew all affection and pushed them into mental isolation. Bettelheim argued that "infantile autism is a state of mind that

develops in reaction to feeling oneself in an extreme situation, entirely without hope” (p.68), and that “the initial cause of withdrawal is rather the child’s correct interpretation of the negative emotions with which the most significant figures in his environment approach him” (p.66). Thus, ‘parentectomies’ were recommended, resulting in children with infantile autism being removed from their parents and placed into foster care, in the hope that the child’s social development would recover (Baron-Cohen, 2008). This had a significant impact on parents, mothers in particular, who were made to feel shame and embarrassment for having a child with autism. Parents became overwhelmed with guilt, and two-parent families were often split by attempts to assign blame to either parent (Wing, 1997).

The era of parent-blaming continued into the late 1950s but gradually began to weaken thereafter as researchers ploughed ahead in their study of the biological and genetic basis of autism (Wing, 1997). The weight of parental blame began to lift from parents’ shoulders when Dr. Bernard Rimland, an American research psychologist, presented conclusive evidence of autism as a biological disorder in his 1964 book “Infantile Autism.” Further, when Folstein and Rutter published their seminal study in 1977, supporting the genetic basis of autism, any notion of autism being the result of ‘cold mothering’ was strongly refuted. Rutter, in particular, was well known for his important studies of families, which found that parents of children with autism were no less caring than other parents (as cited in Baron-Cohen, 2008). Although emerging scientific evidence challenged the theory of ‘cold mothering’ it did not completely eradicate it, and, unfortunately, it has taken many decades for parental guilt to diminish (Baron-Cohen). Advances in autism research have supported the neurobiological basis of autism in addition to the profound stressors experienced by parents in their struggle to parent their child with autism (DeMyer, 1979). These advances helped significantly in turning the tide on any

lingering theories of parental blame and helped change parents' self image from seeing themselves as the primary cause of their child's autism to co-therapists, their child's developmental agent, and special advocate (Schopler & Mesibov, 1984).

Putting Asperger's on the Map

When Dr. Lorna Wing, an English psychiatrist, published her ground-breaking study in 1981, the term "Asperger's Syndrome" was coined and the work of Hans Asperger became popularized. Wing (1981) advocated for AS to be embraced by the medical community as a valid diagnostic term after she had assessed and diagnosed 34 individuals, ranging in age from 5 to 35 years old, who shared the same characteristics described by Asperger. Further, Wing advocated for 'Asperger's Syndrome' as a neutral term compared to Asperger's original term 'autistic psychopathy of childhood' with its intonations of sociopathic behaviour. Wing, in collaboration with Dr. Judith Gould, (1979), positioned AS on the autism spectrum, and argued that autism was dimensional in nature, existing along a spectrum of variable severity. In 1991, Uta Frith, an English developmental psychologist, translated Dr. Asperger's paper into English, introducing it for the first time to the English-speaking community. Then, in 1992, AS became an official diagnosis as it was added to the 10th edition of the World Health Organization's diagnostic manual, the International Classification of Diseases (*ICD-10*), and subsequently, in 1994, to the American Psychological Association's 4th edition of the Diagnostic and Statistical Manual of Mental Disorders (*DSM-IV*). This was an important step in giving diagnostic legitimacy to AS, and helping families who had previously felt alone with their problems.

AS is currently recognized in the *DSM-IV* as one of five ASCs, also known as *Pervasive Developmental Disorders*, which include *Autistic Disorder*, *Pervasive Developmental Disorder-Not Otherwise Specified*, *Rett Syndrome*, and *Childhood Disintegrative Disorder*. With the

expected release of the *DSM-V* in 2013, major revisions have been proposed to the category of ASCs, one of which eliminates AS completely and folds it under the broad diagnostic label of ‘Autism Spectrum Disorder’ on a severity scale (Wallis, 2009). This proposed change to the diagnostic nomenclature has generated heated debate and controversy, prompting the argument that more individuals with AS will fall through the diagnostic cracks and not receive the understanding and intervention they need. Further, the proposed change prompts the question of what will happen to the individuals currently diagnosed with AS and their families. As a result, significant changes will likely occur in our understanding of AS, and the care provided to individuals with AS and their families, into the future.

In considering that AS is a relatively new diagnosis, the state of research on this complex condition continues to be in the exploratory stage with a significant gap in empirical research addressing parents’ experiences. The following section will present a review of the research on parenting experiences in relation to AS to set the stage for the current study.

Parenting Experiences

Obtaining the Diagnosis of Asperger’s Syndrome

On average, children with AS receive a diagnosis much later in their development at 11 years, compared to children with autism who are diagnosed at 5.5 years (Howlin & Asgharian, 1999). As early identification and intervention are key to promoting successful outcomes for children with ASCs (Butter, Wynn, & Mulick, 2003), a late diagnosis of AS may increase the vulnerability of these children to poor health outcomes later in life (e.g., development of co-morbid conditions), and adversely impact families caring for them. The families of children with an ASC, including AS, may follow different pathways in their pursuit of a diagnosis for their child. For some, the diagnostic journey may be smooth where symptoms are detected at a young

age and a diagnosis is given; however, others may be full of twists and turns, dead-ends and roadblocks (Nichols, Moravcik, & Tetenbaum, 2009).

It has been noted that a diagnosis of an ASC, including AS, does not come until years after parents start looking for one (Mertz, 2005). In their large survey of 770 families of children with ASCs in the UK, Howlin and Asgharian (1999) found that from the time of first becoming concerned to finally obtaining a diagnosis, parents of children with AS had to wait more than twice as long as parents of children with autism, with an average of 8.59 years (SD 5.92) compared to 3.97 years (SD 4.29) respectively. In waiting over several years for an accurate diagnosis, families of children with AS may become perplexed and disillusioned with a system that proves unhelpful (Nichols, Moravcik, & Tetenbaum, 2009). Further, many individuals with AS are not diagnosed until well into adulthood (Ehlers & Gillberg, 1993; Gillberg & Ehlers, 1998). This sheds light on the need for greater public and professional awareness of AS in order to recognize it earlier in childhood, and intervene accordingly to support families in need.

In the several pathways to an AS diagnosis, as described by Attwood (2007), only one pathway smoothly led to the diagnosis of AS in the early years. The other pathways involved a delay of many years before the diagnosis of AS was obtained, a protraction that can persist into late adolescence and adulthood. Along the way, parents may receive an inaccurate diagnosis for their child before receiving the accurate diagnosis of AS. This was revealed in Huang's (2007) dissertation that used grounded theory to explore eight parents' experiences pursuing a diagnosis for their child with AS. Huang's study found that all children were inaccurately diagnosed at an earlier age (3-7 years) before receiving the accurate diagnosis of AS at an older age (5-15 years). In this study, the most common inaccurate diagnosis or 'other label' received by children was Attention Deficit Hyperactivity Disorder. These 'other labels' may apply to the child but do not

accurately describe the child's complete profile. As the symptoms of AS may be confused with other conditions, and there are no medical, genetic, or definitive psychological tests for the condition, it is rare to smoothly attain an AS diagnosis (Mertz, 2005). Delaying the receipt of the accurate diagnosis of AS results in difficulty experienced by children with AS and their families in acquiring essential knowledge, skills, and services to effectively manage the AS.

Impact of a Delayed Diagnosis

Several studies have shed light on the impact of a delay in diagnosis on parents of children with AS (Chell, 2006; Gray, 2002; Lasser & Corley, 2008; Portway & Johnson, 2003). Howlin and Asgharian (1999) found that parents of children with AS experience more frustration and greater delays in their search for a diagnosis than parents of children with classic autism. Parents who voice their concerns for their child may be dismissed by professionals who are reticent to attach a label (Chell, 2006) or reassured that there is nothing to worry about and that their child will grow out of it (Howlin & Asgharian, 1999). This can leave parents feeling isolated with their problems, minimizing their need for help and denying them access to appropriate services and supports to enhance their ability to manage AS. Further, in their quest for a diagnosis parents may be unduly judged by teaching staff and professionals who focus on the child's verbal and cognitive abilities and question parenting skills (Brewin et al., 2008; Schormans, Renwick, Ryan, & Lim, 2005). When the child does not behave, think, or play as other children do, extended family members and school staff may conclude the child is intentionally being bad and that such rude and selfish behaviour is a result of poor parenting. This can bring forth challenging emotions for parents such as guilt, shame, isolation, and despair (Chell, 2006).

In Portway and Johnson's (2003) qualitative study of twenty-five families who had young adults, 18 to 35 years, with AS, the average age of diagnosis was 12 years. This study illuminated how a late diagnosis can place a burden on families who care for children with unexplained differences. In several studies, this notion of a "hidden disability" was discussed (Brewin et al., 2008; Chell, 2006; Lasser & Corley, 2008; Portway & Johnson), referring to an underlying vulnerability masked by the seemingly normal appearance of the child. This invisible nature of AS often baffles and confounds parents who are caught in a paradox of sorts, in which their children give the outward semblance of normality, and may even charm others with their extensive vocabularies and specific areas of interest, yet are disabled in subtle yet profound ways (Portway & Johnson). Some parents wished their children with AS had Down Syndrome because the disability would be more visible to others (Chell, 2006; Gray, 2002). The hidden disability and delay in diagnosis are unique challenges for parents raising children with AS.

Parental Reactions to the Diagnosis

As there are no studies that specifically focus on parents' reactions to their child's diagnosis of AS, this section will draw upon the few studies that broadly focus on parents' experiences raising a child with AS (Chell, 2006; Lasser & Corley, 2008). In the small body of literature on parenting a child with AS, parental reactions to the diagnosis are varied, ranging from a resistance to the diagnosis (Chell) to a profound relief in having a name for their child's difference (Lasser & Corley). In Chell's focus group study of 13 parents (10 mothers, 3 fathers) of young people with AS, the issue of diagnosis was identified as a key theme. Prior to receiving their child's diagnosis, parents questioned their parenting ability and believed they were paranoid in worrying about their child's difference. Parents spoke to how the diagnosis confirmed their observations of their child's difference, and validated the reality of their experiences. Further, the

diagnosis was “like a ticket” (p.1353) in that it helped parents gain passage to helpful services and supports for their child and family. This was reiterated in Lasser and Corley’s grounded theory study of 20 parents(19 mothers, 1 father) of children with AS, with parents noting that the diagnosis “validated their concerns, provided them with a word for what they had observed, and directed them to a constellation of resources specifically to address their needs” (p.342). Although parents in both studies spoke to the positive aspects of receiving their child’s diagnosis, the parents in Chell’s study spoke to its painful impact and demonstrated a resistance to the diagnosis and its implications for their child. For these parents, the diagnosis confirmed their suspicions of something being “wrong” (p.1353) with their child, and they feared their child being labelled as ‘different’ from others.

Although these studies shed some light on parental reactions to their child’s diagnosis of AS, they are exploratory in nature and tend to homogenize mothers’ and fathers’ reactions under the umbrella term ‘parents.’ As Kingston (2007) aptly inquired, “Why do we use the generic term ‘parents’ in scientific research on families, when the vast majority of research participants are in fact mothers?” (p.17). In considering the limited research on the differences and/or similarities between mothers’ and fathers’ experiences in the context of raising a child with AS, more research needs to target fathers as well as mothers to specifically address this gap.

Parental Stress and Asperger’s Syndrome

Recent quantitative studies have shown parents of children with AS experience a significant amount of stress (Epstein, Saltzman-Benaiah, O’Hare, Goll, & Tuck, 2008; Mori, Ujiie, Smith, & Howlin, 2009). This significant amount of parental stress has been linked to child characteristics such as problem behaviours (Mori et al., 2009), and associated features of AS such as sensory sensitivities (e.g., heightened perception of touch, smell, taste) and executive

functioning deficits (e.g., problems with goal-directed behaviour, planning, working memory, multi-tasking, and flexibility) (Epstein et al., 2008). In Epstein et al.'s study, mothers and fathers of children with AS were found to experience comparable levels of stress although a significant relationship between parenting stress and child characteristics was found only for mothers. It remains unclear why fathers' stress levels were not significantly related to their child's characteristics but researchers theorize that fathers may experience stress differently than mothers (Epstein et al.). Thus, further attention is needed in qualitative research to explore fathers' as well as mothers' experiences raising a child with AS, deepening understanding of the challenges that are uniquely stressful for parents of children with AS and how they can best be supported.

In addition to child characteristics being linked to parental stress, the experience of stigma has also been described as a significant source of stress for parents (Chell, 2006; Gray, 2002). Chell's focus group study of parents' experiences raising a young person with AS found isolation and stigma to be a key theme as parents described being isolated, unsupported, and even blamed for their child's condition. According to these parents, lack of understanding and awareness in the general population and among professionals exacerbated the emotional impact of parenting a child with AS. Lise Pyles, in her book "Hitchhiking Through Asperger Syndrome" (2001), reveals her wish for others to understand and accept her son as she does, stating "If I could cure anything, it would be to cure the world of its lack of understanding" (p.69). This lack of understanding is pervasive, and can extend from encounters with family members to interactions with professionals. For example, extended family may believe they can cure the child of his/her condition or may deny the reality of the condition, and health care professionals

adhering to the mechanics of assessment may not be sensitive to parents' feelings and imply that parents are to blame for their child's problems (Chell).

In his study on the nature of stigma and how parents of children with AS or high functioning autism (HFA)¹ cope with it, Gray (2002) distinguished between felt stigma, defined as feelings of being rejected or shame, and enacted stigma, defined as overt displays of rejection or discrimination. Gray's study found that a large majority of parents do experience felt stigma, over 75% stating that others were critical of their child-raising abilities, and about 50% experienced enacted stigma, experiencing avoidance, overtly hostile staring, and rude comments. Mothers in particular were noted to be more likely than fathers to experience enacted stigma (Gray, 2002). As Gray's (2003) study found, mothers of children with HFA were more likely to be the primary caregivers, largely responsible for the domestic tasks, child care, and liaising with health care professionals while fathers were more likely to take on a peripheral role, immersing themselves in their work and keeping their children busy with activities when at home. As a result, the gendered division of roles and responsibilities may provide a plausible explanation for the differences between mothers' and fathers' experiences of stress and stigma.

Although Bettelheim's theory of autism as a reaction to inadequate parenting and failure of parent-child bonding has been rejected, and the term "refrigerator mother" has been dispelled (Baron-Cohen, 2008; Gray, 2002), there appears to be a prevailing stigma experienced by parents, mothers in particular, that they are to blame for their child's AS. This calls for greater awareness and understanding of parents' experiences raising a child with AS. It is egregious that despite advancements over the years in autism research, there continues to be such pervasive stigma and lack of understanding, particularly among health care professionals (Chell, 2006).

¹Gray (2002) does not delineate between AS and HFA, viewing the two terms as synonymous. Whether AS is a qualitatively different and distinct condition from HFA remains controversial (Klin, McPartland, & Volkmar, 2005).

This calls forth the need for more research on parenting a child with AS to increase awareness and deepen understanding of parents' experiences, challenging the stigma that continues to pervade lay and professional communities.

In exploring parents' experiences of stress, researchers have found that parents of children with AS may be at high risk of experiencing mental health challenges such as depression and anxiety, and may require psychotherapy and medication (Little, 2002; Stoddart, 2005). According to Dillenburger, Keenan, Doherty, Byrne & Gallagher (2010), parents of children with an ASC, including AS, are nearly three times more vulnerable to psychological ill health than the general population. In his quantitative study examining depression and anxiety in parents of children with AS in Ontario, Stoddart (2005) discovered that mothers were at high risk of experiencing depression and anxiety, which may result from grieving the loss of a "normal child," experiencing the stresses of raising a child with AS, and a natural proclivity to anxiety and/or depression. Of the 60 parents he recruited for the study, 36.7% revealed a history of mental health challenges, and 33.3% of mothers and 25% of fathers had been prescribed medication for these mental health challenges, most notably depression and anxiety. These findings are comparable to a previous study by Little (2002) that found 45% of mothers and 26% of fathers of children with AS had taken anti-depressant medication. Thus, the limited evidence suggests that parents of children with AS experience high levels of stress and are at significant risk of developing mental health challenges, specifically depression and anxiety. Mothers are particularly vulnerable.

In reviewing the literature on AS, few studies identified whether parents' had male or female children (Chell, 2006; Portway & Johnson, 2003), and those that reported the male to female ratio did not explore the parenting experience in relation to the gender of the child with

AS (Brewin, Renwick, & Schormans, 2008; Lasser & Corley, 2008). As Nichols, Moravcik and Tetenbaum (2009) state, “Although there are obvious similarities between the experiences of male and female children with ASD’s [Autism Spectrum Disorders], the parents of daughters face unique issues (e.g., menstruation, degree of vulnerability, social and cultural expectations for behaviour) and often lack a supportive outlet within which to share their concerns and hopes, as well as resources for seeking assistance” (p.28). As parents of daughters with AS face unique issues, it is important that these issues are understood in order to tailor services and supports to better meet the needs of this population. As a result, research needs to target families with female children with AS.

The literature on parenting a child with AS contains themes ranging from difficulty attaining a diagnosis, significant levels of stress, encounters with stigma, and increased susceptibility to mental health problems. However, there is little available research addressing the complete experience of raising a child with AS, including both the challenging and positive aspects from mothers’ and fathers’ perspectives. In reviewing the limited literature on parenting a child with AS, the findings are largely descriptive (Chell, 2006; Little & Clark, 2006), and focus on specific aspects of the parenting experience such as the wonders and worries (Little & Clark) or experiences of diagnosis, treatment, and service provision (Chell, 2006). Further, they tend to meld AS under the broad spectrum of autism (Altiere & VonKluge, 2009; Huws, Jones, & Ingledeu, 2001; Phelps, Hodgson, McCammon & Lamson, 2009; and Woodgate, Ateah, & Secco, 2008), conflate it with HFA (Gray, 2002, 2003), or combine it with learning disability (Benderix, Nordstrom, & Sivberg, 2006; Little & Clark, 2006), limiting insight into the unique experience of parenting a child with AS.

In reviewing the literature, only one study was found specifically addressing the process of parenting a child with AS (Lasser & Corley, 2008). This study drew upon grounded theory to explore three key issues: the challenges faced by parents of children with AS, how parents meet these challenges, and how parents make meaning of their parenting experiences. Semi-structured interviews were conducted with 20 parents, all mothers but one, who reported having a child with AS. The core concept that emerged was constructing normalcy, referring to how parents' make meaning of their child's diagnosis and work to construct a normal life for their child. Lasser & Corley found that when parents first noticed something different about their child's development or received feedback from others regarding concerns, they engaged in a process of meaning-making using reference points. These reference points became external standards of normalcy as parents were noted to compare their child to his/her siblings or to other children, and to seek evaluations from specialists. In social settings, parents experienced critical moments in which others who had previously assumed the child was 'normal' began to see the characteristics of the disability. These 'normalcy incongruities' created social tension for parents as others observed a child of 'normal' physical appearance exhibiting 'abnormal' behaviour, and were prone to judge parents for failing to exert sufficient discipline. These normalcy incongruities were noted as particularly stressful for parents. Further, parents noted how they worked hard to construct a normal life for their child within the home, school, and community settings, helping their child develop the skills needed to be successful.

Although Lasser & Corley's (2008) study sheds light on parents' experiences raising a child with AS, it is exploratory in nature, and thus further research is warranted to better understand parenting a child with AS in the context of family life. Further, this study is marked by several limitations. Firstly, the sample was dominated by mothers with only one father being

represented, limiting insight into fathers' experiences raising a child with AS. The authors did not acknowledge this important limitation, and used the generic label 'parents' in discussing the findings. Secondly, this study recruited parents of largely male children (n=18) as compared to female children (n=3), and did not acknowledge the differences, if any, between parenting male and female children with AS. Thirdly, this study involved individual interviews with parents and abstained from sharing whether parents were from dual parent families. Thus, it is unknown how parents managed their child with AS in the context of family life, and whether parents were able to share the responsibility of constructing normalcy with a partner or spouse. Lastly, the parents self-identified as having a child with AS and therefore there was no means of confirming the diagnosis. These limitations open the door for more research addressing mothers' and fathers' experiences raising male and female children with AS, and support the importance of this work.

Significance of Study

This review of the literature supports the need for a more complete understanding of parenting children with AS. As parents of children with AS experience significant stress and are susceptible to mental health challenges, they represent a particularly vulnerable population. Further, more children are being diagnosed with AS than ever noted before, and, as a result, more families will be in need of services and supports to help address their needs and enhance their ability to manage AS. As the prevalence of AS continues to rise, health care professionals such as nurses will likely encounter children with AS and their families in diverse practice settings, and require knowledge of parenting children with AS to better support families and help them manage the basic issues relevant to AS (Inglese, 2009). Above all, the gaps in the literature on parenting children with AS, as presented above, support the timeliness and importance of

gaining a better understanding of parenting from the perspectives of both mothers and fathers of both male and female children.

Summary

In this literature review, an overview of AS was given in terms of its diagnostic profile, differentiating it from classic autism. Further, an historical account of AS was given with a specific focus on parents' experiences, and how our understanding of parents' roles and responsibilities in raising a child with AS have changed with evolving research. Key issues experienced by parents of children with ASCs, with a specific focus on AS, were discussed, ranging from the delay in diagnosis to parental stress, mental health, and stigma. Overall, this literature review provides the basis for conducting this study, identifying what is known about the phenomenon of interest and unveiling the existing gaps in the literature. The following chapter will explain the methodology of this study, specifically articulating how it was designed to address the key gaps in the literature and make an original contribution to the state of the research on parenting a child with AS.

CHAPTER THREE: RESEARCH METHOD

This chapter will present the research method and discuss the different stages of the research process. In addition to describing interpretive description, the qualitative approach informing this study, this chapter will review the following topics: selection criteria, recruitment process, description of participants, data collection, data analysis, ethical considerations, locating the self, credibility and rigour, and limitations.

Theoretical Underpinnings

This study drew upon a qualitative or ‘interpretive’ method of research to address the phenomenon of interest. According to Denzin & Lincoln (2005), qualitative research involves an interpretive, naturalistic approach to the world. This approach is also called for when little is known about a topic of interest. Through sampling participants who are experts on the topic of interest and by using the data collection method of in-depth interviewing, I gained an insider view of parents’ experiences raising a child with AS. Further, the analysis focused on identifying common themes and patterns across parents’ experiences, reflecting a qualitative aim to make sense of and understand human experience (Thorne, 2008).

This study drew upon the specific qualitative approach of interpretive description (Thorne, 2008). Interpretive description aligns with the interpretive approach as it acknowledges the constructed and contextual nature of human experience while allowing for shared realities (Thorne, Reimer Kirkham, & MacDonald-Emes, 1997). Interpretive description reflects the aim of this study which is to explore and describe how parents experience raising a child with AS, noting the varying degrees and dimensions of their experiences and the similarities and differences. Interpretive description moves past mere description and allows for meanings and explanations to be generated, thus enhancing clinical understanding (Thorne, 2008). Interpretive

description has a pragmatic focus in which the findings generated are relevant to clinical practice and have application potential (Thorne, Reimer Kirkham, & O’Flynn-Magee, 2004). This pragmatic focus is congruent with the ultimate goal of this study which is to provide direction for services and supports that will enhance families’ ability to manage AS.

Selection Criteria for the Participants

Purposive sampling was used to recruit families based on the following eligibility criteria (Appendix II):

Inclusion Criteria

- 1) Mothers and fathers of male and female children with AS who were between 11 and 19 years
- 2) Child had a confirmed diagnosis of AS
- 3) Family had known the diagnosis for a minimum of 2 years and a maximum of 6 years
- 4) Fluent in English
- 5) Resided in Kelowna, Vernon, or Salmon Arm

Exclusion Criteria

- 1) Parents of children with a concurrent diagnosis of AS and a medical and/or psychiatric condition such as epilepsy, diabetes, non-verbal learning disorder, attention deficit hyperactivity disorder, depression, anxiety, and psychosis.

The reason for recruiting mothers *and* fathers of male *and* female children was grounded in the literature on ASCs that reveals a dominant focus on mothers’ experiences without adequate attention given to fathers’ experiences. Further, AS is diagnosed more often in males than in females, and thus the limited literature on parenting a child with AS privileges families of male children over female children. The age parameters were set based on 11 years being the average

age of diagnosis (Howlin & Asgharian, 1999), and recognition that the adolescent period is a particularly challenging time for parents raising a child with AS (Tantam, 1991). Further, there are significant changes in service provision that occur once the child is a legal adult; therefore, parents of adult children were excluded as a way to manage the complexity of the study and enhance feasibility. Parents who had known their child's diagnosis for between 2 and 6 years were recruited as this provided time for parents to adjust to the diagnosis, develop knowledge and skills in relation to the diagnosis, and gain familiarity with and access to the services available. Further, as only a few years had passed since receiving their child's diagnosis, parents were able to easily call forth and speak to their experiences of parenting a child with AS. The recruitment areas included Kelowna, Vernon, and Salmon Arm. Recruitment in multiple geographic locations in the Okanagan and Shuswap areas insured that more families met the eligibility criteria, and thus enhanced the feasibility of recruiting eight to ten families. Parents of children with concurrent medical and psychiatric conditions were excluded to understand parents' experiences specific to raising a child with AS.

Recruitment Process

Parents were recruited through service agencies, one support group, and newspaper advertisements and articles in Kelowna, Vernon, and Salmon Arm. The service agencies and support group were all focused on addressing and meeting the needs of families raising children with ASCs. The support group was open to all families who self-identified as having a child with an ASC. Five families were recruited from Kelowna, two from Vernon, and one from Salmon Arm sampling sites.

At each sampling site, eligible families were recruited in two ways: 1) an email was sent by a designated employee with a letter of introduction and invitation to consider participating in

the study (see Appendix III for Letter of Introduction and Invitation). The letter of introduction and invitation included contact information for interested families; and 2) families were told about the study by the professional at each of the sampling sites, and if they expressed interest in learning more or in participating they signed a consent to contact form (see Appendix IV for Consent to Contact Form) that was forwarded to the researcher. Advertisements (see Appendix V for Advertisement) were given to the designated employee at each sampling site to share with eligible families, and to post on bulletin boards. Advertisements and articles were also placed in both free and subscription-based newspapers within Kelowna, Vernon, and Salmon Arm. Although I encouraged parents interested in the study to refer other parents for participation, all parents were recruited through professionals at the service agencies and support group, as well as through newspaper advertisements and articles.

Description of Participants

All participants met the inclusion criteria. Participants were parents of children between the ages of 11 and 19 years who had been diagnosed with AS. All families had a child with a confirmed diagnosis of AS, as they were all receiving, or had received, autism funding, which, according to BC requirements, requires a confirmed diagnosis by a qualified specialist (e.g., paediatrician, child psychiatrist, or registered psychologist) (Dua, 2003).

The following tables summarize the demographic information for the parent participants and their children:

Table 1. Parent demographics.

Families recruited	8
Dual parent families	8
Number of mothers	8
Number of fathers	5
Age of parents (years), (mean±SD)	46.64 ±7.31
Mothers' age (years), (mean ±SD)	46.25 ± 7.76
Fathers' age (years), (mean ±SD)	47.67 ± 7.37
Cultural Identity	Number of families
Caucasian	8
Mother's Education	Number of mothers
High School	2
College	5
Graduate Study	1
Father's Education	Number of fathers
College	2
Graduate Study	1
Not Reported	5
Income (Annual)	Number of families
\$25,000-\$50,000	1
>\$50,000	4
Not Reported	3
Mother's Job Status	Number of mothers
Employed	5
Unemployed	2
Retired	1
Father's Job Status	Number of fathers
Employed	5
Not Reported	3

Table 2. Child demographics.

Number of male children	6
Number of female children	2
Age of children (years), (mean ±SD)	14.75 ±2.49
Age of female children (years), (mean ±SD)	16.5 ±3.53
Age of male children (years), (mean ±SD)	14.17 ±2.14
Age at diagnosis (years), (mean±SD)	10.75 ±2.87
Years known diagnosis (mean±SD)	3.87 ±1.46
Living with parents	7
Living independently	1

Data Collection

Data were comprised of semi-structured interviews with parents, demographic information for each parent, and field notes. Parents were given the choice of conjoint or separate interviews, which ranged from one to three hours in length. Individual interviews were chosen by mothers when fathers could not participate due to work or household-related responsibilities. For example, in the first family, the father was unavailable to join the first interview due to work-related responsibilities; however, he was available for the second interview. Parents were interviewed at least twice in a quiet, private place of their choosing. Five families chose their homes as the most convenient place for the interviews to be held, and three families chose a quiet, private room at the university, a church, or a service agency (not associated with the service agencies utilized in this study for recruitment).

The following table summarizes the data collection:

Table 3. Data collection.

Family	Interviews	Participants involved
Family 1	Interview 1 Interview 2	Mother Mother and Father
Family 2	Interview 1 Interview 2	Mother Mother
Family 3	Interview 1 Interview 2	Mother Mother
Family 4	Interview 1 Interview 2 Interview 3	Mother and Father Mother and Father Mother and Father
Family 5	Interview 1 Interview 2	Mother Mother and Father
Family 6	Interview 1 Interview 2	Mother and Father Mother
Family 7	Interview 1 Interview 2	Mother and Father Mother and Father
Family 8	Interview 1 Interview 2	Mother Mother
Total Number of Interviews	17	
Number of Individual Interviews	9	
Number of Conjoint Interviews	8	

Multiple interviews offered the opportunity to clarify and confirm my understanding as I returned to the participants. The first interview was guided by the interview guide (Appendix VI), and follow-up interviews were guided by questions that arose in the first interview. This helped clarify my understanding and achieved parental verification of the interpretation of their experiences. The open-ended interview questions were designed to encourage parents to speak in free-flowing narrative with minimal prompting and follow-up questioning from myself as interviewer. A third interview was available to follow-up with parents as needed in case any further information or clarification was required. A third interview was only offered to one family as the first two interviews were limited in time, and the questions had not been fully answered. The interviews were audio-recorded, transcribed verbatim, and accuracy checked.

This process enabled immersion in the data and facilitated the analysis. A demographic form (Appendix VII) was completed by each participant after the first interview. The decision to stop recruitment was made in conjunction with my supervisor when concurrent analysis showed consistent and well-supported themes in the data that clearly addressed and answered the research question.

Field notes were recorded for each interview, and were formatted using the template provided by Morse and Field (1995) as a guide (Appendix VIII). According to Morse and Field, field notes are necessary for a successful qualitative study and must be “detailed, accurate, and extensive” (p.112). The electronic recording of the interview captured words that could be transcribed verbatim onto paper but did not capture the physical setting of the interview, impressions of the observer, or nonverbal communication (Morse & Field). Thus, field notes played an important role in supplementing the in-depth, semi-structured interviews.

Data Analysis

The data were analyzed using the analytic method of constant comparison (Thorne, 2008) derived from grounded theory methodology (Glaser & Strauss, 1967). This method involved constant comparison of every piece of data (e.g., an interview, a statement, a theme) with all others, noting any similarities and differences between them (Thorne, 2008). According to Thorne, constant comparison helps uncover the commonalities and patterns across cases within human experience. The commonalities and patterns emerged through systematically coding each transcript for meaning, probing the data further by asking critically-oriented questions such as “What is going on here?” and “Does what I think I see fit the reality of the data?” (Strauss & Corbin, 1998, p.45). This process of questioning facilitated the coding of parents’ experiences, fracturing the data, breaking it apart and digging beneath the surface for meaning (Strauss &

Corbin). The actual coding of the transcripts involved ascribing a specific term or signifier to each data chunk (Thorne, 2008).

As the coding ensued, taking the time for reflection greatly assisted in making sense of the data. As Glaser (1965) states, “The analyst should take as much time as necessary for reflecting and taking his thinking to its most logical (grounded in the data, not speculative) conclusions” (p.440). Analytic memos were used to facilitate this reflective process. Analytic memos are notes written into a blank notebook that allow the interpretive mind to reflect on and record insights as they evolve over the analytic process (Thorne, 2008). Using analytic memos to record the evolving interpretive insights helped clarify thoughts and ideas around what I was seeing in the data.

Joint coding and frequent meetings with my supervisor assisted in the review and discussion of the coding process. The most frequently occurring codes were identified and additional codes and sub-codes were added as necessary, helping to refine the coding and move the analysis forward. As the analysis moved forward, the codes were organized in a logical sequence and located under descriptive headings to establish a coding framework. This helped show the relationships between the codes as similar codes were grouped together, and clear definitions were developed for each code.

The coding framework was confirmed by team members on the thesis committee. Each member was given a different transcript to code to determine whether the framework was reliable and strong enough to hold. Once the coding framework was considered stable, all transcripts were coded using NVivo data management software. Codes sharing similar characteristics were grouped together into larger units called categories or themes. As the codes became categories, the analysis became more refined, moving from the descriptive level to a

more abstract, conceptual level. Data analysis continued after data collection stopped until a coherent interpretive description of parents' experiences was rendered.

Ethical Considerations

Designing and conducting qualitative research brings forth a number of ethical issues. The ethical considerations, both generic, such as obtaining informed consent and protecting participants' anonymity, as well as situation-specific (Marshall & Rossman, 2006), will be outlined as follows. Ethical approval was obtained from the Ethics Review Board of UBC Okanagan. Participants signed informed consents (see Appendix IX) at the outset of the study and verbal consent was obtained on an ongoing basis (Thorne, 2008).

The information provided by participants was kept confidential and did not affect their access to services. Service and support agencies were not informed of the families who decided to participate. The letter of introduction and invitation, consent to contact form, and newspaper advertisements provided my contact information for interested families to directly contact me. Participants were informed that any complaints or concerns they shared during the interviews would not be disclosed to any service and support agencies. Further, participants were informed that there were no funding ties to these agencies.

As a number of situation-specific ethical issues may arise from the relationship between researcher and participant, these issues were reflected upon and responses were planned. A few participants inquired about my own interest in the research topic. I was sensitive to sharing this information during the interview since this had the potential to divert focus away from the participant(s) and limit the information the participant(s) would share with me. However, I was also aware that self-disclosure could enhance the information gathered by building trust and rapport with the participants. Therefore, I offered some limited disclosure regarding my personal

and professional interest in AS if asked directly. For example, three families specifically asked about my motivations for doing this research, and I responded by sharing my professional experience working with children who had AS and their families, and my personal experience as a sibling of a brother with AS. This information was shared at the end of the interview to preserve the flow of interview questioning, and avoid detracting from the data collection process. Further, I was aware that this conversation could influence subsequent interviews, and I openly discussed this concern with participants. I reminded participants that I was interested in their experiences, and that there was no right or wrong way to experience raising a child with AS.

In two families, the mothers exhibited tearfulness in recounting distressing experiences, and were offered the choice to take a break from, end, or continue with the interview. The mothers chose to continue with the interview, and were able to continue speaking about their experiences. All participants were offered a list of supports for parents of children with AS (see Appendix X) at the end of the first interview. Further, there was a check-in at the end of each interview with participants that allowed for time to reflect on the impact of the interview, noting what stood out the most, exploring questions that were not asked, and adding anything that may have been missed.

In the process of interviewing, I was aware of navigating the tensions between the role of researcher and role of nurse. As one of the key mandates of nursing is to help those in need, promoting health and wellness and alleviating illness and suffering, I experienced tension when, in the midst of interviewing, families posed questions to which I knew the answers. My initial reaction was to help these families who expressed a strong need for more information such as how to utilize their autism funding and access services and supports for their child with AS. Although I was conscious of my primary role as researcher, and my goal was to obtain rich data

to answer my research question, I also acknowledged my professional background as a child and youth mental health nurse and grappled with how to ethically respond to these situations where issues of role confusion and duality of identity were brought forth. I navigated this tension through engaging in praxis, reflection in and on action, in which I recognized how the values of nursing are embedded within my own way of being as a researcher, and thus I responded to families' need for information by answering their questions at the end of the interview. Although the role of researcher is one of investigation and not counselling or education, I believe that it is impossible and undesirable to completely distance the self from participants, especially considering the trusting relationship that develops in the context of the qualitative interview where participants openly share their experiences (Robinson & Thorne, 1988).

Locating the Self

As the qualitative researcher is considered the 'primary instrument' of data collection and analysis, it becomes vitally essential to locate the self as researcher (Rossman & Rallis, 2003; Thorne, 2008). Locating the self is based on the assumption that "our own experiences and perspectives influence every aspect of the research we do" (Gilgun, 2010, p. 2), and therefore we need to make these experiences and perspectives explicit to conduct sound research. I will frame these experiences and perspectives in terms of personal, disciplinary, and theoretical orientations, shedding light on how these orientations inform this study.

Throughout the research process, I was acutely aware of my personal orientation, and the need to account for my personal experience with the phenomenon under study. As the sibling of a brother with AS, I understood the importance of identifying assumptions, beliefs, and biases based on my sibling experience, and exploring how they might shape the research in important ways. This was an ongoing task and was facilitated through reflexivity during and after

interviews in which I attuned myself to the questioning and rapport-building with families, and reflected afterwards on the reciprocal interaction between myself as researcher and the families. I practiced ongoing reflexivity through field notes and memos to assist in exploring personal values and beliefs and their impact on research processes (Maxwell, 2005). Through this process I became aware of how personal experience can influence the research enterprise in subtle yet significant ways. For example, during the data analysis I found myself captured by the resiliency within parents' narratives and my coding began to reflect a dominant focus on the positive aspects of raising a child with AS. However, this was not capturing the full extent of raising a child with AS, as described by the parents in this study. In recognizing and challenging this privileging of the positive, I began to identify a tacit assumption that families are inherently adaptive and shift their perspectives based on their experiences with an inflexible child. This was an a priori theory of parenting arising from personal experience within my family that was entering into the data analysis, and through engaging in reflection I was able to identify and challenge this assumption, keeping it in check to avoid its imposition on the findings. Through keeping my mind open and curious to seeing new possibilities in the data, meeting frequently with my supervisor to discuss the research as it progressed, and engaging in ongoing reflection, I was able to uncover and challenge assumptions, biases, and personal beliefs, hold them in abeyance, and thus minimize their unintended impact on the research as it progressed (Thorne, 2008). This process did not represent the quest for objectivity but to cultivate reflective skills to facilitate the credibility and rigour of the final work (Ahern, 1999).

As the theoretical orientations of social constructivism and family systems theory were previously discussed (see CHAPTER ONE), this section will focus on disciplinary orientation. The disciplinary orientation of child and youth mental health nursing influenced my interest in

exploring parents' experiences raising a child with AS. Through working with children with AS and their families, I came to see the myriad challenges parents face in reaching a diagnosis, accessing services and supports, and managing their child with AS. As parents asked questions about how to obtain autism funding, where to go to access services, and how to manage their child's social and behavioural challenges, I recognized the difficulty parents experience in raising a child with AS and the myriad unanswered questions they have. My interest in family nursing care in the context of child and youth mental health spurred me towards researching parents' experiences to strengthen the services and supports they receive and enhance their ability to manage a child with AS. Although this disciplinary orientation informs and supports my interest and motivation for doing this research, it may also create bias, leading to preconceived ideas about what parents experience based on clinical patterns I observed in practice. In recognizing the potential for these preconceived ideas to influence my understanding of parenting a child with AS, I engaged in reflective journaling throughout the research process to account for this bias, identify when it may be entering the research, and keep it in check. Further, prior to and during each interview I reminded myself to keep an open and curious mind about what parents experience in raising a child with AS, writing this reminder on my interview guide. I also informed participants who were aware of my previous work in the field of child and youth mental health that there is no right or wrong way to experience parenting a child with AS, and that I was interested in finding out their experiences as parents in raising their child with AS. These strategies assisted in keeping any disciplinary bias in check, and demonstrating a commitment to the integrity of this research.

Credibility and Rigour

In evaluating the credibility and rigour of an interpretive descriptive study, there are four key evaluative criteria, as outlined by Thorne (2008). Firstly, the research must exhibit *epistemological integrity* in which there is a unifying thread that seamlessly weaves together the epistemological assumptions, research question, and methods for data collection and analysis. This provides a “defensible line of reasoning” (Thorne, 2008, p. 223) that allows the researcher to make transparent and defend the congruent and logical nature of the research design and process. Epistemological integrity is apparent, and may be evaluated, in the congruence between my research question, theoretical framework, and research method.

In addition to epistemological integrity, the research must show *representative credibility* in which there is congruency between the claims made and the way in which the phenomenon under study was sampled (Thorne, 2008). This notion of ‘representativeness’ relates to the degree to which the findings of a study may be exported to provide an explanation for the experiences of other individuals within comparable situations (Horsburgh, 2003). This is supported through a careful description of the sample, which provides readers with a clear picture of the individuals sampled and their demographic variables, and helps them determine if their situations are comparable. Thorne (2008) recommends a number of strategies that may further support the representative credibility of a study, including: maximal variation, prolonged engagement in the field, triangulation of data sources, and a consideration of knowledge from multiple angles of vision. To build representative credibility into my study, a variation of perspectives was utilized in which I purposefully sampled mothers and fathers of male and female children with AS. Multiple interviews were conducted over time, allowing for in-depth

engagement with participants. Further, an in-depth description of the sample was provided to assist the reader in determining the representativeness of the sample.

The third evaluative criterion is analytic logic, which demonstrates the reasoning process extending from the forestructure (Miles & Huberman, 1994), or pre-understanding of the phenomenon of interest at the outset of the study, to the interpretations and knowledge claims made (Thorne, 2008). As the inductive analytic process ensued, myriad decisions were made. To support the decisions being made, analytic memos and frequent meetings with my supervisor explicitly accounted for the reasoning process. Ensuring this process is transparent allows for an audit trail that can be followed by readers of this study who are interested in evaluating the adequacy of the decision-making process and the credibility of the findings. It is my goal that clinicians in the field reading this work will nod their head in approval with the interpretations made as they find the claims plausible, confirmatory of clinical “hunches,” and able to illuminate new relationships and understandings (Thorne et al., 2004). My thesis committee provided an external check of the research process (Creswell, 2007) to ensure the findings are plausible, useful, and meaningful (Thorne et al., 2004).

The fourth evaluative criterion is *interpretive authority*, which involves the researcher taking responsibility for the interpretations made and grounding these interpretations in the data to show their trustworthiness. Interpretive authority was supported by two strategies. The first strategy was immersion in the data, which involved reading, reflecting upon, and writing about the data in detail. Immersion in the data was demonstrated through transcribing the interviews and checking them against the recording for accuracy, writing field notes after each interview, and writing memos during the analysis to record interpretive insights. The second strategy was through participant involvement and eliciting feedback on emerging interpretations. As data

collection and analysis occurred concurrently, I was able to check my evolving interpretations with participants, and revise them as needed for accuracy. This process of checking my interpretations during the interviews helped in not only clarifying my understanding of parents' experiences but in keeping the interpretations grounded within parents' experiences.

In addition to drawing upon these criteria to evaluate rigour and credibility, a more subtle critique may be taken that considers the larger context within which the research findings were produced. This entails consideration be given to the *moral defensibility*, *disciplinary relevance*, *pragmatic obligation*, *contextual awareness*, and *probable truth* of the research (Thorne, 2008). *Moral defensibility* considers how the findings will be used in society, determining to what extent they may promote the well-being, and alleviate the suffering, of specific subsets of the population. This criterion is based upon the assumption that in a practice discipline such as nursing, knowledge is not produced for knowledge sake but for the purpose of benefiting others in need, and therefore should ultimately improve a social circumstance. The findings must also demonstrate *disciplinary relevance* and be useful to advancing the state of disciplinary science. In addition to this disciplinary lens, the researcher must attend to the practice context, demonstrating *pragmatic obligation* to generate findings that hold application potential in the clinical realm. As Thorne, Reimer Kirkham and O'Flynn-Magee (2004) state, "A good piece of research will make sense of something that clinicians ought to understand" (p. 8). This aligns with the goal of interpretive descriptive research, which is to generate findings that can inform practice within the applied health disciplines. Through the process of engaging in research, it is important to demonstrate *contextual awareness*, which gives the researcher an appreciation for the contextual nature of the findings, acknowledging that they are not fixed in stone but may be subject to change over time depending on the context in which they are produced. A final

measure of credibility entails looking at how truth is defined in the research study, and whether the tentative nature of the truth claims made, essentially their *probable truth*, are acknowledged.

Through articulating these areas for deepening the critique of this study, it is my assumption that the reader will draw upon them as a benchmark for assessing this study's rigour. The use of quotes in the findings chapter (see CHAPTER FOUR) will invite the reader to assess how the findings are grounded in the data, looking at the contextual nature of the findings and the probable truth within parents' narratives. Further, the discussion chapter (see CHAPTER FIVE) will invite the reader to examine the moral defensibility, disciplinary relevance, and pragmatic obligation of this study as it will showcase the application potential of the findings, delving into the key implications for practice, education, and research.

Limitations of the Study

The limitations of this study are:

- 1) The recruitment of eligible families was achieved largely through newspaper articles and advertisements, thus privileging a particular subset of the population who have the time, energy, and resources (e.g., education, income, level of confidence) to access a newspaper, respond to a research advertisement, and participate in a research study.
- 2) The sample criteria sought families who could easily communicate (i.e., read, speak, and write) in English as this was the primary language of the researcher, and therefore excluded non-English speaking families from participating.
- 3) The sample size was not large enough to account for gender variations in parents (e.g., between fathers and mothers) or between parenting male or female children.
- 4) More interviews were conducted with mothers than fathers, which may have biased the findings.

5) The sample was homogeneous (e.g., socio-economic status, education, race, ethnicity, family configuration, geographic location), limiting understanding of families from diverse backgrounds.

Summary

This chapter discussed methodological issues, describing the qualitative approach of interpretive description and presenting the research design. The methods for data collection and analysis were discussed along with ethical considerations, locating the self as researcher, and standards for evaluating the rigour and credibility of this study. This research design will provide the necessary context for interpreting the findings in the following chapter.

CHAPTER FOUR: FINDINGS

In this chapter, parents' experiences raising their children with AS will be presented and explained through the concept of a balancing act. This balancing act is comprised of three key themes: losing our footing, regaining our balance, and helping others find their balance.

Losing Our Footing

The balancing act begins with 'losing our footing,' which is a process that occurred over time as parents experienced increasing problems in raising their children with AS, and struggled to find helpful answers to explain their children's differences. In this section, the process of losing our footing will be presented, and will include a discussion of the following experiences: noticing differences, running into problems, searching for answers, encountering parental blame, seeking professional help, receiving unhelpful answers from school and health care professionals, persevering through the problems, and experiencing crisis points.

Noticing Differences

Many parents first noticed their children's differences in the infant and preschool years. During these early years, parents observed their children's differences from what was considered typical or 'normal' child behaviour.

Mother: I knew he was different right from when he was little because even in preschool he wouldn't play the same way as what I thought other boys would do. (Family 1)

Father: I won't say that [Child with AS] was ever a quote unquote 'normal' child, because she was always different from the other kids in what she excelled at and what her interests were. (Family 7)

The most common difference was the child's difficulty fitting in with others. Many parents described their children's quiet nature and preference to play alone.

Mother: He wasn't rambunctious, he was always very quiet and very much to himself, and he could wander around outside in the yard with one little stick with a play thing for

hours on end and not be distracted. He didn't generally like to play with toys that I figured were common with boys. (Family 1)

Mother: He was always a bit of an odd child, you know, not really interested in too many play dates or getting out and doing stuff. (Family 8)

Two families described how their child was expelled from daycare because of difficulties fitting in with others. While for the first family it was the child's overtly quiet nature and withdrawal from peers that created problems, for the second family it was the child's aggressive behaviour towards a peer that resulted in being expelled.

Mother: When he was 3 we were asked to not send him back to daycare because he was too quiet and always withdrew, and didn't want to participate with the other kids, like when the kids were all playing playdoh, he wanted to read a book, and then once those kids moved onto another activity then he'd be happy to play playdoh, but he never wanted to do anything in a group. (Family 3)

Father: We knew that he was probably a little more aggressive than some of the other kids out there, that's why he got expelled from daycare, there was another kid who was playing with his toy, and [Child with AS] wanted the toy...and asked very nicely "Can I see the toy?" and the little boy wouldn't let him share it, so he picked the boy up and dropped him on his head and took the toy and walked away. (Family 6)

In addition to their children's quiet, socially awkward and reclusive nature, parents noticed their children's pursuit of singular interests and activities.

Mother: She did other things too, they were single person things, like she took swimming lessons and excelled at that, and she rode horses. (Family 7)

Mother: I noticed in playschool, I would come to pick him up and the teacher would say 'Well, he's doing whatever but he just doesn't seem to want to join in the group.' He'd be over playing in the sandbox on his own or doing things more on his own. (Family 2)

Parents noticed how their children would engage in unusual, often repetitive behaviours such as finger flicking, drawing pictures, and lining up toys.

Mother: He would walk about, pace the floor, wave his hands in the air, swishing we called it, and making strange noises, and talking to himself in his room. I don't know why that should be annoying because it's not a big deal but you know when you see a child doing that you think what are his school friends going to think if he does that in school? (Family 1)

Father: She'd fill up pages and pages and pages and pages of the same drawing, and go through a box of computer paper in like 2 months, doing the same drawings over and over and over again. It progressed from little amoebas with little tails, and moved on to something else, but it was always something that carried on for, the dinosaurs went for a long time. (Family 7)

Mother: When he was younger, he'd line up everything, and when he played with his cars when he was little, they would go into his room and they would all be lined up in a straight row in front of his bed. That's how he was playing, it was like lining them up all nice and straight. (Family 8)

Further, parents also noticed their children's intellectual differences from same age peers, noting advanced memory skills, exceptional ability to concentrate on tasks for long periods of time, strong pursuit of interests that exceeded their age level, and extensive vocabulary.

Mother: When he was watching a documentary about animals, a two hour documentary, about 6 months later he comes up with some obscure information about some obscure snake that I had never heard of and I said "How do you know that?" and he said "It was on that show I watched." And it was like months later. (Family 1)

Mother: She was very, very smart in many ways, very talented as an artist, at that age she wrote a little book when she was in preschool, her preschool teacher still has it...we've got a copy of it somewhere but that's not something that the average child does. (Family 5)

Mother: Even when he was little, he always had a very good vocabulary and always talked way above his age compared to the other 3 year old kids, like he wasn't doing the baby talk, you know, it was full sentences and put together. (Family 8)

Initially, parents dismissed their children's differences as they could be reasonably explained and managed. Parents believed they had a "normal" child with "unique" qualities, and thus did not deem the differences to be problematic or "significant." As a result, parents could handle these differences, and were not prompted to seek professional consultation or intervention.

Mother: I didn't really worry about it at the time. I just figured well, he's got a different personality so we'll see how things go. (Family 1)

Mother: We always knew there was something there, like there were certain things that we would just kinda shake our head and carry on. So it's not like we were clueless, it was just that it didn't have significance. (Family 3)

Mother: We just dealt with these issues and thought well, she's a little different, and we just humour her and try and get through the day. (Family 5)

Father: We knew before school that there were differences, how he was dealing with other kids, we knew beforehand but we just didn't, new parents, every person is an individual, every person behaves in a different way. (Family 6)

Parents viewed their children's differences in the context of their own childhood, remembering when they had experienced similar idiosyncratic behaviours and social difficulties. As a result, these parents could identify with, and accept, their children's differences, and they rationalized that their children would outgrow these differences with advancing age.

Father: I was much the same, even though I did lots of social things with kids, and games, I still was much like [Child with AS], preferred to spend a lot of time to myself, alone, so I didn't think it was that abnormal either. (Family 7)

Mother: I was a little concerned through all of her early years that she wasn't very social, but because she was happy I wasn't too worried about it 'cause I had been the same way, so I thought, I turned out all right [laughs] so eventually she would learn those skills, so I wasn't too concerned. (Family 7)

Parents took comfort in knowing their children were intellectually capable, and excelled in areas that other children did not.

Mother: Because he was really smart I wasn't worried that he had some sort of a learning disability or anything like that because I already knew from young on that he had a very good memory. (Family 1)

Father: I kinda thought we were lucky because she seems smarter than all our friends' kids, she was reading second grade books and chapter books by the time she was in kindergarten. (Family 5)

There was also a reticence to interpret the differences as problematic, and pursue professional help.

Father: You know, looking back on it now, we thought, oh isn't that cute, ha ha, she keeps herself so busy (with repetitive drawings), what a wonderful child! But it was

obviously obsessive behaviour, but you don't want to look at stuff like that because your kid is perfect, they're the best kid in the world. (Family 7)

Most parents were not overly concerned during their children's early years. Although a few parents questioned their children's behaviours and raised their concerns with others, they were often told that their children were going through a "phase" or that the behaviour was "natural."

Mother: We'd hear "oh, all kids sometimes go through phases where they only want to eat macaroni and cheese and that's not really abnormal," and I'd be like "Okay, it's not that [Son with AS] doesn't want to eat it, it's just he says he can't," and [the doctor] is like "Well it's just a phase. Just keep giving it to him and eventually he'll eat it"...and so it didn't seem like, from one side as a parent, that there was enough concern there to really warrant us getting worried about the behaviours that we were seeing for a while when he was younger. (Family 3)

Mother: I think it was still pre-school where I would bring [Daughter with AS] home, I think it was the babysitter's, and she would scream steady for 2 hours after I brought her home so I was really concerned, and I never talked to the MD, but I talked to the babysitter and I talked to other moms, and they suggested that it was just the kid is so good all day that it's kind of natural to have a spell where they're letting out all their frustrations. (Family 7)

A few parents felt that if there was a significant concern with their children, then others would bring it to their attention or would inquire further.

Mother: [Daughter with AS] went to preschool, so every day she was in a half a day with other kids, doing crafts and things, so you think that one of those caregivers would notice something if there was something to notice, and she just went through the system. (Family 7)

Mother: If we go shopping and we get into a car and he starts talking about what happens if the car crashes, and I could express that to the doctor then if that's significant the doctor's gonna ask me more about that or is gonna ask him about that, and that wasn't happening. So I guess as parents we started to think, both me and my husband were like, "Okay, well maybe it's just typical, like maybe it's not significant." (Family 3)

Overall, with one exception, for most parents their children were quiet, polite, and appeared to be happy playing alone and pursuing isolated interests. As their children were well-behaved and could entertain themselves, parents were not concerned. One mother explained it this way:

It's a blessing when they're your first kid and they'd rather read a book than go to the park, so it wasn't that we really thought, "Mmm, there's something really wrong there," you know. There probably was lots of warning flags and we just didn't see. (Family 3)

The early differences were not unsettling for parents as they were able to find reasonable explanations for the differences. As long as the differences were not viewed as problematic parents were able to carry on parenting 'as usual.'

Running into Problems

When the early differences became exacerbated and new differences presented, parents began to have problems with parenting their children. The differences that became problematic for most parents to manage included their children's rituals and routines, sensory sensitivities, social difficulties, and school problems.

Many parents observed their children's insistence on rituals and routines, upholding the need for consistency and sameness, and demonstrating a strong aversion to the slightest change. This was very frustrating for parents as they could not understand the reason for their children's inflexible insistence on rituals and routines, and they struggled to manage the 'meltdowns' that would ensue if the rituals and routines were not followed.

Mother: There were certain things that started out as fun but then it became a daily ritual that had to be done every day, and she'd get upset if it didn't. One day I was bringing her home from the babysitter and we'd stop at the red light and wait for it to turn green, and one day we didn't stop at the red light and we just went through on the green, and she was so upset... We got home to the driveway and she was just screaming. I had to turn around and go back and wait for the red light to turn green [laughs] so that we could come home, otherwise she was just not going to accept it. (Family 5)

Some parents became uncertain in their ability to parent, and, when they questioned the right thing to do as a parent, the answers were not forthcoming.

Mother: [Child with AS] had very strict schedules like when he ate cereal I had to use a blue bowl with a purple spoon and I had to pass it to him with my right hand. I could not pass it to him with my left hand without him having a meltdown, and the doctors couldn't explain to me why [laughs]. I'm like "But why?" and they're like "Well, he's just

decided that that's the way it needs to be and he's just being stubborn so we encourage you to pass it to him with your right hand and get him to understand that it is still okay to eat the cereal even though you have passed it with your right hand," and he couldn't, and so he wouldn't eat breakfast for 3 weeks, and then I'd be calling my doctor again going "Is this okay?" because it's affecting his health now, and they're like "Oh, well we can't really tell you" [laughs], and it was frustrating. (Family 3)

In addition to rituals and routines, sensory sensitivities were noted by many parents who described their children's acute perception of, and discomfort within, the sensory environment.

Mother: We started to see a lot of sensory issues, so the hearing and the touch. He didn't want anybody to touch his head, and so that manifested all of a sudden at home we'd say "Take a shower" and the water was too cold and it was too hot, and then you can't wash me with soap because it's fuzzy and I don't like that feeling, and I don't want you to touch me. (Family 3)

Mother: He would just get overloaded, just completely overloaded with sensory input and of course we didn't know that this was bothering him, we didn't know that these lights, he tells me they're flickering, I can't tell that they're flickering but he can tell that they flicker and it bothers him. (Family 4)

Mother: Just for him to sit in class, he couldn't filter out the lights, the sounds, he could hear twenty pencils scratching at the same time, people's feet moving and he couldn't focus. (Family 6)

Parents struggled to understand why their children became upset with sensory stimuli such as touch, taste, light, and noise, and they were unable to find the source of their children's problems. One mother explained it this way:

So we started to see all this sensory stuff happening and then at the same time it was like his clothes weren't right and he couldn't eat that kind of food because it was too squishy, and he couldn't eat that food because it was too crunchy, and we're like "What is going on?" As parents we had no idea, right. (Family 3)

In trying to figure out how to manage their children on their own, many parents tried to change their child's behaviour, which was unsuccessful. As one mother explained, "We were completely unable to handle it a lot of times because we just didn't understand, and we kept thinking logically you shouldn't be feeling this way, and we're telling you why you shouldn't be feeling this way."

Parents became increasingly puzzled by their children as the sensory sensitivities did not go away but became worse, and began to present in the school environment. One mother described how her son adamantly refused to attend school because of the unpredictable sensory environment. Everything from the rustling of paper in the classroom to the sound of chalk against the chalkboard was upsetting. Another mother described how her son had to touch the carpet in the classroom before sitting down, gauging whether he could tolerate its texture.

In addition to the rituals, routines, and sensory sensitivities, many parents noted their children's social difficulties, specifically getting along and fitting in with peers.

Mother: It didn't bother me until he started getting into school and started struggling with social issues and then not knowing why, and that's when it started to bother me, and I figured something needed to be done. (Family 1)

Mother: When she was in school and started having problems with the other kids, just things had to be her way and if someone interfered with that she would be more likely to get upset more easily in school. (Family 5)

A few parents described how their children were an 'easy target' for peers who could readily perceive and provoke their triggers at any opportunity.

Mother: There were always altercations at school and he would come home beat up, and they'd learn how to trigger him, and he would come home with his hands covered in scabs and stuff, and I'd find out what was going on, and he said the kids would stab him with scissors and stuff, and he'd be bleeding. (Family 6)

Father: I showed up at the end of volleyball practice, and all the other girls were coming out of the change room, and there was no [Child with AS], so I was looking for her ... and when I finally did get her to come out, she had been crying for like a full hour, she had been in there really tormented about the treatment she got from the girls. They really picked on her because she was taller than all of them but they were all better volleyball players. (Family 7)

These problems were stressful for parents as they could not understand why they were occurring, and they did not know what they could do to help their children. One mother explained it this way:

Every day we had to talk about something that had gone on and how to deal with it, and so quite often we were dealing with problems that she was having and it's frustrating, you know, just having problems but not really knowing exactly what to do. (Family 5)

Several parents described their children's problems at school, most commonly sharing how their children would interrupt and dominate class discussion.

Mother: The school called me in and I guess the teacher said to him, "What makes you think that you should call out?" The teacher was frustrated, this is Grade 1, and said "What makes you think that you know all the answers?" and he said "Because I'm smarter than everyone else," and he said it very matter of factly. He didn't mean it in any negative way, to him it seemed obvious that "Oh well, I'm smarter than these other children, and you're asking a question, why don't you want me to answer." (Family 4)

Mother: The teacher did get frustrated, it was difficult having her in the classroom, she would always put her hand up, and [the teacher] knew that she knew the answer but wanted to give other kids the chance to answer, and if he didn't call on her she would get upset, and then she would stomp or slam books or something. So she had difficult moments in the classroom at that time. (Family 5)

Mother: His teacher said in class she had to get to the point where she could only ask him once in a while because she would ask him a question and he would give an hour's spiel [laughs], and he would know the answer to everything. (Family 2)

In addition to classroom interruptions and lengthy monologues during teaching lessons, parents noted how their children could not sit still in the classroom. Parents described frequent phone calls from teachers regarding their children's disruptive and distracting behaviour in the class such as 'crab-walking' between desks and pacing at the back of the class. This was a confusing and distressing time for parents as they struggled to understand and effectively manage their children's behaviours. One mother explained it this way:

Everything was just kind of snowballing, schooling was getting harder, I was getting phone calls about him not being able to sit in his seat and he was getting angry and I'm like "He's what?" 'cause that's not at all who he is, and so we started to see these behaviours that were scary for us 'cause we didn't know where they were coming from. (Family 3)

When parents began to run into problems, they became increasingly challenged in their ability to parent successfully. While most families experienced a gradual build-up of problems

over time, a few families experienced a sudden onset of problematic behaviours from their child.

These families described the sudden, startling shift in their child's behaviour as follows:

Mother: [Child with AS] had a very short window where we went from like okay to not okay, and it was like "Whoa, like what happened?" So probably the second half of kindergarten we started to see other signs, the "I don't like school" became much bigger, it wasn't just a phrase he was using, it was meltdowns. (Family 3)

Father: She was such a happy child and we just kept on doing the things that made her happy so when it did turn, and the behaviours started at the start of high school it was such a shock. I could show you a hundred pictures of [Child with AS] up until the age of say 12 or 13, and not once will you see her without a smile on her face, and a natural smile, like a happy smile, genuine, and [3 second pause] just like turning on a light switch, and so right away "Oh my God! What's going on here?" (Family 7)

Only one family experienced a problem that was not experienced by any other families.

This problem involved self-harm in which the daughter with AS engaged in 'cutting.' This prompted the family to know that there was something "wrong" with their daughter, and served as the catalyst event, spurring them to search for answers.

During this time of running into problems, parents became uncomfortable and uncertain in their parenting, questioning their ability to parent successfully and not knowing where to go or what to do to help their children. This was when parents became unsettled in their ability to parent, and thus began the process of 'losing their footing.' When parents began to search for answers, most encountered numerous difficulties such as parental blame and unhelpful responses from professionals, and some reached crisis points, which served to further 'unbalance' them. Parents' experiences of searching for answers will be discussed next.

Searching for Answers

As the problems presented and began to worsen, parents began to eagerly search for the answers they needed to understand, explain, and help manage their children's behaviours.

Parents' experiences associated with searching for answers will be presented in this section.

Encountering parental blame.

In not knowing the reason for their children's problems, many parents looked to themselves for answers and this often included self-blame.

Father: Before we really knew what the problem was we just thought, "What's going on with this boy? Why is he having these problems?" And so, at that time, it really seemed like this incomprehensible thing, what are we doing wrong? (Family 4)

Father: Your first instinct is to blame yourself for something that you're doing that's making the situation the way it was. I don't know if I ever looked at it as trying to fix [Child with AS], because the last thing you want to think when you're in a situation like that is there's something wrong with your child. (Family 7)

Mother: You do, you carry that guilt for a long time. You say, "Well maybe it was that. Maybe it was something that I did," and in my particular case huge amounts of guilt and blame because I had a lot of difficulties when I was pregnant with him...during that time, when you don't have a diagnosis yet, you're looking for places to blame and you're thinking "Well, maybe it's all my fault because I let them give me the drugs in the hospital because the pain was so bad and I couldn't cope anymore, maybe it's my fault, so you carry a huge amount of guilt and blame. (Family 6)

Without a diagnosis, many parents wondered what they had done to cause their children's problems, and felt guilty and helpless in not being able to do anything to help their children.

Mother: You feel helpless. You want your child, I mean, any parent wants their child to behave a certain way, and that's probably one of the hardest things about being a parent, is accepting that your child doesn't always behave the way you want them to or think they should but more extreme with someone with Asperger's. It is very frustrating because you can't make them behave the way other kids do, and people do wonder, you know, what's wrong with that kid? Or why does she not behave the way other kids do? (Family 5)

Father: It's almost like you've lost your child, and probably no different than if they had died, the strife and the feelings of guilt and the feelings of helplessness that you have, like what kind of a parent am I? I can't do anything to help my child. (Family 7)

A few parents blamed each other, questioning each other's discipline style and communication skills.

Mother: You blame each other, anytime there's a problem, particularly when there's a child, you're looking where's the blame, not because you want to blame another person but when you can find who to blame you can find a solution, 'cause sometimes you can get rid of that problem. So, I don't think it's done on purpose but you're looking to find

the problem, and then, in looking to find the problem, you're blaming somebody. So, I think for us, it was like "Well, your parenting style is too lax," "Well, your parenting style is too harsh," "Well, you don't communicate very well," "Well, you do this," so there's a lot of blaming. (Family 6)

As the children misbehaved and had meltdowns in public spaces, an audience of others (strangers, extended family, professionals) also blamed parents for allowing the misbehaviours, and not properly disciplining their children. Thus, the typical answer to the question of "What is happening here?" was inadequate parenting. This occurred both before and after the diagnosis as parents encountered others who did not recognize or understand their children's differences.

Mother: Sometimes as parents, I think it seems we get criticized a little bit differently, and parenting can be seen as 'Oh, that behaviours because you're not disciplining your child,' or it's because you're not following through, when it's really not any of those things, it's just something completely separate of that, so those things can become quite frustrating. (Family 3)

This judgment and criticism from others often exacerbated parents' feelings of self-blame and guilt.

Mother: There were many nights I was crying saying "It must be me, it must be me," and it's not helped by the fact that when he would have a meltdown or an outburst when he was younger, there were certain people who said to me, "Well, you shouldn't have stayed home with him for 4 years 'cause kids benefit from being in preschool and daycare," so that was my fault, and then there was a whole other faction of people, once I put him into daycare who were saying "You shouldn't put him in daycare. You should be at home with him." You can't win, you know, it's that Mom guilt. (Family 4)

While most parents experienced instances of direct parental blame (e.g., judgmental remarks and 'dirty' looks), a few parents noted instances of perceived parental blame where they sensed or had an intuitive feeling that strangers were judging their parenting. One mother explained it this way, "I got such a bad feeling sometimes thinking that people would think I was a very bad mother and not bringing my child up to be polite because that's what it looks like" (Family 1). In sensing negative judgement and blame from strangers, and feeling responsible and embarrassed for their children's problems, some parents apologized.

Mother: I apologized on his behalf on several occasions because he had been, what I thought was really rude to people, and I don't tolerate that. (Family 1)

Mother: I suppose you do feel helpless and maybe apologetic that, you know, "Sorry she behaved that way." I remember once she went to a birthday party with a group of kids that she'd been going to school with since kindergarten, and I left her at the party... She just got extremely upset about something so when I went to pick her up, and the Mom told me, I felt so bad that I'd left, I felt like "Geez, I should have stayed. I didn't realize. I didn't think she would have such a big problem." (Family 5)

Parents not only experienced negative judgements from strangers and acquaintances, but also from extended family. Many parents explained how extended family had difficulty understanding and accepting their children's behaviours, and thus judged and blamed them for not implementing sufficient parental discipline and properly controlling their children's behaviours.

As a result, parents chose to limit their encounters with these family members, and a few mentioned that this judgment had created a rift in their relationship with extended family. Even after obtaining their children's diagnosis, a few parents explained how extended family members refused to acknowledge or understand the condition, continuing to believe the answer to their problems was a lack of effective parenting.

Mother: It's really hard, like my own Mother doesn't believe in Asperger's, she just says "Oh, it's a behaviour problem, you just need to be stricter," so it has caused a rift in our family but people either accept it or they don't, and there's not much you can do about it, except try and educate them if they're willing. (Family 2)

Mother: [Husband]'s Mom is a good example, she doesn't understand it, she doesn't get it. She never will. She's basically said that I'm just too tough and too hard on [Child with AS], and I should lay up a bit and stuff like that. (Family 8)

When parents sought answers from school and health professionals, voicing the problems and concerns they had with their children, many were not taken seriously, blamed for imagining or exaggerating the problems, and not parenting "well enough."

Mother: Without the diagnosis it's kind of like hearsay, like "That's just what you think" but it's not really proven, so you think he has a hard time in a classroom, you think he has

a hard time making friends, you think he's bothered by the noise in the gym, but really he's a kid and he's gonna push your buttons and he's just doing this so he doesn't have to do his work. You think he can't print very neatly but maybe he's just doing it because you don't make him do it, so it almost becomes like this, "Well maybe you're just not parenting him well enough." (Family 3)

A few parents were encouraged to enrol in parent training and read parenting books to learn how to effectively discipline their children, and therefore remedy the problem.

Mother: We had problems with discipline, and different things like that around the house, and everyone we went to kept saying "Oh, you know it's parenting, it's parenting," I was like "We are consistent," you know, "We do things." So then we took the [parenting course], and then we took another one, and it was like "Okay, after 3 parenting classes, I don't think it can be just us, [laughs], there's something else." (Family 8)

However, parents noted that these were unhelpful answers as they did not reduce or eliminate the problem. Parents found it confusing and frustrating when professionals implied that inadequate parenting was the answer because they knew that they were strict enough parents. As the professional spotlight shifted away from the child and towards parenting, some parents became defensive.

Mother: Well, at first the doctor, every once in a while, would say, "Oh, you know, it's the parenting, and he's just maybe a very stubborn kid," and it's like, "No, I'm not a nice Mom, I'm a mean parent [laughs], he's not getting away with stuff." (Family 8)

When professionals continued to offer up unhelpful answers related to inadequate parenting, parents felt alone and abandoned with their problems.

Mother: That's the very first reaction is that this is a parenting skills issue or an environment issue at home, so it's yours to deal with, or you need to get this child under control. We said, "Look, we can understand that if we were low income or uneducated or we weren't good parents or there was a divorce in process, or some stressors at home, but there isn't any stressors." (Family 6)

Two families gave detailed accounts of their experiences with Social Services after their child made claims of child abuse. These families explained how they were blamed by the

‘system’ when professionals immediately believed they were guilty without further investigation.

One father described the complexity of the issue this way:

[Child with AS] ran away, made a bunch of these accusations to social services, and we were both treated like we were guilty, they would not tell us where she was, they would not tell us anything, they just automatically assumed that [Child with AS] was telling the truth, and we were made victims of the system. Now, I understand that you have to be somewhat careful because a lot of times people make accusations that are true, but I think they went really overboard on it. (Family 7)

Parents had difficulty defending their ability to parent as they did not have the AS diagnosis or any helpful answers to explain their children’s problems.

Mother: We were called in, my husband and I, we were called in to Social Services because they said “Oh, [Child with AS] said [Husband] yelled at him.” Well, I mean, [Child with AS] tends to blow things out of proportion, once we found out the autism that’s so typical that everything is a big deal kinda thing. At the time, it was just awful. (Family 2)

The claims of abuse resulted in one child being placed in alternate housing, and kept apart from the family. This was a difficult time as the parents worried for their child’s safety, powerless to help their child or participate in her care. The father explained it this way:

We had no control over her care and her safety, none. It was taken away from us, and we were basically guilty until proven innocent by the system. (Family 7)

In this situation, the family actively searched for and eventually found their child, bringing her back to the family home.

During this difficult time, parents were desperate for the answers, and did not know how to explain the problems to themselves or to others. When the most common answer to the question of “What is going on here?” was that the problem was with the parents and their parenting, this undermined the parents’ confidence in their own abilities and knowledge. It created a ‘no win’ situation for both the parents and the children, and the problems persisted, which contributed to the process of ‘losing our footing’ as parents. Throughout repeated visits to

school and health professionals aimed at seeking assistance, most parents not only encountered parental blame but experienced a range of unhelpful answers, which will be discussed next.

Seeking professional help.

In seeking help from professionals, only one family experienced a direct and smooth path towards a diagnosis of AS for their child. After the child's social collapse at school, the mother voiced her concerns to school professionals, and a referral was made to the regional autism assessment and diagnostic clinic where the diagnosis of AS was determined. The mother recounted this experience of receiving a helpful answer in the following quote:

I asked the principal if she could refer us to the district counsellor, which of course she did right away. They filled out all the paperwork, and then the counsellor came on board. She had a short session with him, and she had a short phone call with me, and then I went in to see her at the school and she said, "I think he has Asperger's Syndrome," and I said "What?" I'd never heard of it before, so she gave me some paperwork on it and she said that you need to do this, this, and this, and get him diagnosed. (Family 1)

This was not the case for most families, however, as they described unhelpful answers from school and health professionals, leading to dead-ends and crisis points.

Unhelpful answers from school professionals.

A few parents described how school professionals did not immediately recognize their children's problems or validate their concerns because their children were pleasant, well-behaved, polite, and studious at school.

Mother: She would draw the same thing over and over and over again, every day for a year, and all those early teachers never thought that's a bit odd but she was quiet and like good in class so they were probably just happy, like me, that she was well-behaved. (Family 7)

Mother: The grade 3 teacher he had was very good, but she had a lot of kids with other disabilities in the class, so [Child with AS] was a dream to her, like there was nothing wrong with [Child with AS], he was good, he did his work...I don't think she saw the other little things because there were too many other kids in the class with problems that she had to deal with. It was just overlooked. (Family 8)

As the problems were not apparent to school professionals, they did not perceive parents' concerns to be legitimate, and, as a result, they were dismissive. Once again, parents found themselves alone and struggling.

Mother: He'd come home and it would be a 4 hour meltdown from the whole entire day that we'd have to deal with once we got home, and so trying to explain to the teachers that that's what was happening at night, and I didn't understand what was happening during the day, and they were like "Oh, he's such a pleasant child. He's such a happy boy," and I'm thinking [laughs] "No, he's not!" They just didn't get that, and that was frustrating because it was like I knew something was wrong but at the same time all the professionals around me thought I was crazy. (Family 3)

When the problems were recognized by the school, parents were not initially informed by school professionals (i.e., teachers, principals). When school professionals ran into problems managing the child they often resorted to punitive measures, which proved unsuccessful. As a result, the problems at school continued to worsen, teachers became increasingly frustrated, and parents remained uninformed and unable to help.

Mother: She didn't do well in track and field but then she would get upset about it, and she'd get so upset that she just had such a hard time dealing with it that they had to make her leave the field and go talk to the principal, and no-one even told me about it until the third week, so I didn't realize this was an issue. I could've been there, and helped out, and tried to make it a little easier, or we could've just pulled her from it, either way, we could've done something differently. (Family 5)

Mother: None of the teachers understood, and situations where disorganization is very common with Asperger's, and instead of helping him or telling us that there was issues they would tape his desk shut and put all his books in a bag at the back of the class, and of course then he gets picked on even more, and the social issues get worse and worse. (Family 6)

When the school did inform parents of the problems, this was often accompanied by frequent phone calls requesting that parents remove their children from school for the day or for extended breaks. Teachers had reached a point where they could no longer manage the disruptive behaviours in the classroom such as altercations with peers and frequent meltdowns. Faced with these frequent phone calls, parents became increasingly frustrated and concerned.

Mother: We were getting calls at home every day and that was causing a lot of frustration in our family because it's like "Why are you doing this!" We are getting these calls from the school and everything, and I said "He needs more to do. Obviously he's bored, he needs more to do." (Family 2)

Mother: I was getting phone calls almost every day, it was very difficult, well, I shouldn't say every day but probably at least twice a week...and quite often I would have to come pick her up before the day was over and bring her home because she was so upset about something. (Family 5)

Mother: In the early days, when he was 6, this sort of incident was actually a lot more common, this hardly ever happens these days, but when he was 6 he was getting in a lot of trouble at school, and every day getting calls from the school, something else had happened. (Family 4)

Parents described how the school was quick to conclude their children were 'behavioural' problems, and thus were 'targets' for both classmates and teachers.

Mother: I think [other kids] knew how to bait him, they knew if I just say something to [Child with AS], once they had gotten him so bullied they'd just look at him and he'd freak out, and of course he's the one that gets in trouble, and the other kid doesn't. (Family 4)

Mother: She would get teased, bullied, because she was an easy target, you didn't have to say or do much to tick her off or upset her, and then she would retaliate 'cause she wasn't able to control that, she would just get upset and just kinda freak out, and she would be the one that would get in trouble. (Family 5)

When parents were repeatedly told by professionals that their children were behavioural problems, they began to further doubt their ability to parent successfully. One mother explained the uncertainty this way:

I think you second-guess yourself and, you know, the medical system or the school telling you that your child is just a behaviour problem. (Family 6)

For some families, the school was unable to adequately protect their child at school. These families experienced serious safety issues, which included their child being injured at school or going missing during field trips.

Mother: He was being beaten up on the bus, and he was coming home hurt but he couldn't explain to us why he was getting in trouble, we just knew that he was getting hurt, and nothing that we did was helping, the school wasn't helping. (Family 6)

Mother: And the first field trip that I sent him on without me I told him that I couldn't be there, I had a meeting or something to go to, so they had an aide who was assigned to someone else going on this field trip, and they said "She can keep an eye on [Child with AS] too," so I found out from another parent, I think it was, the next day, that they actually lost him on the field trip, up at the river. (Family 2)

When a few parents began to pose explicit questions to the school regarding what they could do and where they should go to help their children, the school did not have answers. One mother succinctly summarized it this way: "When you say to the school 'Could you please help us? We will do anything and whatever it takes but tell us where to go at least,'" and there's nothing." Even when parents clearly identified the help they needed from the school such as an Individualized Education Plan (IEP) or a Certified Educational Assistant (CEA), they were denied help. Many parents gave examples of their concerns and requests for help not being taken seriously by school professionals.

Mother: I had a big thing with the school, they didn't think he needed an aide, and I went on every field trip from the time he was in kindergarten to probably about Grade 7 or 8, and I finally thought "You know what, what would they do if I wasn't able to come on these field trips, to stay with him?" I mean, they counted on me coming and being with him, yet they said he didn't need someone with him to supervise him. (Family 2)

Mother: The altercations, and him being kicked out, and from year to year sitting down with the principal and going "Can we please get an IEP? Can we please get a plan in place? What is there available?" We begged, and we said, "Look there's a history here, can you pull the file from last year?" and they said "Oh, for privacy we can't pull the paperwork from last year." I said "This child's been in the school for 3 years now, there's got to be something else we can do. We know he's very bright. We know something's wrong. Will you please help us," and they kept saying "Well, he's just violent, he's just bad." (Family 6)

In response to their continued unsuccessful efforts to receive helpful answers from the school, two families decided to "go it alone," removing their child from the public school system, and choosing home and private schooling options.

Mother: We reached a point where we just said “Sorry school, it needs to be different for him,” and we finally made the decision to home-school [Child with AS]. (Family 3)

Mother: He was just being coded as severely disruptive; I can’t remember the exact code, severe behavioural problem. They still hadn’t done any psychological testing, nothing, like I was just blown away, they just did the coding and that was that, and that’s when I pulled him out, that’s when we did it on our own... and we paid for everything. (Family 6)

When these families informed the school of their decision, they noted the school’s disappointment, and sudden, surprising eagerness to help. Parents did not feel the school’s response was a genuine attempt to help their children but rather an attempt to keep their children’s ‘special needs’ funding.

Mother: When we went to the school and said “We’re actually gonna take him out” it was amazing in that moment how things suddenly changed again because now suddenly the teachers were willing to get him support and they were willing to find help for him and, and as a Mom I’m like “Okay, now I’m just frustrated and annoyed because 2 weeks ago he didn’t qualify for 4 months but now I’ve said I’m gonna pull him out and now he can have help right away. Well why is that?” Well, because when I pull him out I also take his funding (Family 3)

Father: I remember, with the principal, I said “You can’t code him,” she said “Well why not?” and I said “Well, because he doesn’t go to your school anymore,” “What do you mean?” I said “I don’t want him coded that way.” Mother: She was very upset that she lost the funding; she wanted the funding, not to help him. (Family 6)

However, this answer carried its own risks. One mother wondered if the alternative schooling option would provide the best fit for her child, and questioned whether they were doing the right thing for both their child and family as a whole.

Mother: It was horrible, scary, as a Mom with a child with Asperger’s I value my breaks immensely. I value people who are willing to kinda take him on for period of time, whether that’s at school or whether that’s a behaviourist that works with him, that time is valuable, and because I have two other kids that I have to try and fit into that time, that time has a totally different value to it. Yeah, it was scary because as much as I knew that the school wasn’t working, I was afraid that I wouldn’t work either (laughs). So it was having fear of the unknown, and what does this need to look like for him? (Family 3)

One family experienced significant financial stress in pursuing private schooling options, costing them \$14,000 a year. This added expense not only exerted a financial impact on the parents but also impacted their typically developing children, diverting financial resources away from helping them pursue their interests.

Mother: We had to pull funds from many places and really adjust our lifestyle, and now our daughter is frustrated 'cause we can't help her much to get going in school. We've been able to sign student loans and stuff but we couldn't give her the start that we would've liked to, and should be able to, with our types of jobs. We couldn't do that for her because so much was spent just trying to help [Child with AS] cope. So, economically it's definitely affected us too. (Family 6)

During this time when parents struggled with unhelpful answers from school professionals, they actively pursued help from health care professionals, primarily their specialized physician (i.e., paediatrician or child and youth psychiatrist). However, these encounters with health care professionals were also not always helpful, and often resulted in parents receiving inadequate explanations, inaccurate and incomplete diagnoses, and unhelpful treatment recommendations for their children. This had a negative impact on parents and their ability to parent effectively, as will be discussed in the following section.

Unhelpful answers from health care professionals.

As parents watched their children's behaviours worsen and struggled with parenting successfully, they also sought the expertise of health care professionals, trusting them to have the answers they needed.

Mother: As school progressed and learning struggles became apparent...other names came up, like autism came up at one point, and I was told by a doctor "Does he walk on his tippy toes?" and I said "Well no," and they're like, "Okay, well then it's not that," and they moved on. So again, in my head, as a parent, I'm thinking "Well, if it was some form of autism...they would've asked me more about that." So, as a parent, I just dismissed that diagnosis and we moved on to other things. (Family 3)

Mother: Not even a paediatrician, like a paediatrician might have recognized something, we were told in hindsight that we had sort of fallen through the cracks 'cause the MD (Medical Doctor) never even referred her to a paediatrician. (Family 7)

Mother: I'd been in to see the paediatrician and I had told her a couple times that I thought something was different or wrong, and she goes "No, no, no, he's just fine, you know, it's this, this, and this." (Family 8)

Health care professionals struggled to provide clear answers to help parents make sense of their children's differences, and direct them towards solution strategies to help their children. Many physicians did not have enough information to diagnose AS, and sometimes they did not have the expertise to recognize its subtle cues. For some parents, their children were "good" during medical appointments and demonstrated a high level of intelligence, which masked the underlying problem. As one mother explained:

I remember sitting in doctors' offices looking at them going "Don't you see what he's doing? You missed it!" Because he was so smooth and so good [laughs]. They'd be like, "So buddy, how are you doing? What did you do today?" and he'd be like "Did you know that if there was an earthquake in India of a 7.8 magnitude it would kill about 50,000 people and level 37% of houses, and that the UN would probably end up contributing about 3 billion dollars to help with disaster relief." Then he would just look at them, and they'd go "Wow! So what are your favourite things to do?" "Oh, I like to watch TV," and I'm like "You missed it, 'cause you asked him a question, and the second he doesn't know that's what you get, you get these little encyclopedia moments." (Family 3)

As parents continued to struggle with managing their children, they described repeated visits to the physician's office, presenting their concerns and hoping that they would finally obtain the answers they needed. Five families received inaccurate diagnoses (i.e., Anxiety disorder, Pervasive Developmental Disorder-Not Otherwise Specified [PDD-NOS], Sensory Disintegration Disorder, Attention Deficit Disorder, Manic-Depressive Disorder) for their child, which often resulted in ineffective medication being prescribed. The inaccurate and incomplete diagnoses proved to be unsatisfactory answers as parents continued to experience problems with their children that they could neither manage nor explain.

Mother: I had gone into our paediatrician and had said, “Honestly, like I don’t discount that all of these things are issues, but is there not an umbrella that holds all of these issues?” [laughs] That we can say “Oh, well this fits into this and this,” like all these pieces are joined, ‘cause as his parents we knew that they weren’t separate. When his anxiety would go up, his sensory stuff would go up, and when his sensory stuff went up, then his ability to learn would go down. Everything was kind of inter-related and yet we were dealing with it all very separately, which in some ways made sense, but in other ways as a parent didn’t really make sense, and we were frustrated as parents at that point....so incredibly frustrating as a parent having to watch and at the same time watching him get worse ‘cause he’s not getting better. (Family 3)

However, many families followed the medication regimens prescribed for their child, sometimes against their better judgment. The following quote demonstrates the uncertainty that one mother felt with the medication prescribed for her child:

Before they did the autism testing, we tried [ADHD medication] and it said right on the medication “Do not give to some of the people with anxiety problems,” which is what we had been dealing with for the last 3 years, which was one of our major concerns. So I phoned the Dr. and I said, you know, “What about this?” He said “Oh, well no, it’ll be fine. Let’s try it.” After about 2 weeks she was getting really upset at school, she got teased. (Family 5)

One father became increasingly frustrated with repeated inaccurate and incomplete diagnoses, and expressed anger and distrust towards the health care system for not being forthcoming with helpful answers.

Father: Early on it was the anxiety disorder or whatever they called that, and I was going yeah, that is pretty much bang on ‘cause she did have anxiety problems, and then when they came up with the ‘PDD-QRMNOS’ [referring to vague ‘Pervasive Developmental Disorder’ diagnosis] I’m like these guys don’t have a clue so they wrote out a bunch of initials and said “here’s what your kid has.” I’m going they don’t have a clue, why are we even listening to them? I was kind of frustrated with the system then. If you don’t have a clue just say we don’t have a clue [laughs] you know, don’t be making up stuff “not otherwise specified.” (Family 5)

Parents described the lack of effective treatments and supports that accompanied the inaccurate and incomplete diagnoses.

Mother: With Pervasive Developmental Disorder-Not Otherwise Specified, there’s no definite guidelines. There’s no help in the school, within the classroom. (Family 5)

Mother: The first doctor we saw, it was Pervasive Developmental Disorder-Not Otherwise Specified, and it was like, “So now what do we do?” and he goes, “Basically nothing, that’s it,” and it’s like “Okay,” and we were sent out of his office, that was it. (Family 8)

Mother: He was being treated for conditions that they thought might kind of fit what was going on ‘cause they never gave him a confirmed diagnosis of anything but we were seeing an occupational therapist for sensory defensiveness and another occupational therapist for developmental coordination disorder, and another therapist for anxiety disorder, and another therapist. So, they had all these people working with him treating very specific things, and we quickly realized that as helpful as that was it was also unhelpful at the same time. (Family 3)

The unhelpful answers from health care professionals led to dead-ends where parents were again at a loss regarding what to do to help their children. This was extremely frustrating for parents as they continued to observe a progressive worsening of their children’s problems while being unable to help. One mother explained it this way:

We went back to the paediatrician and said “I value everything that you’ve done and are doing but there’s still something missing,” and him honestly not being able to tell us what that is, like as a doctor he would say “We know there’s something there, and we will find it, I just don’t know how long it’s gonna take us to figure it out,” and how frustrating that is as a parent, ‘cause at the same time we knew every day mattered with whatever he was dealing with. (Family 3)

Families expected the public health care system to provide helpful answers to help solve or ‘fix’ their problems. When these answers were not offered, families became increasingly frustrated.

Mother: I think as a culture we kind of expect certain people and professions to have the answers that we need when something doesn’t work, and I think doctors can get the short end of the stick ‘cause we think if something’s not working or if something’s broken, that they know what it is, and they’re gonna ask me the right questions to get the right answers, and, when the doctors don’t have those answers, it’s incredibly frustrating. (Family 3)

Mother: A part of the frustration is being raised in a system where there are answers and there are fixes, right, in the medical system, and so you kind of expect that. (Family 7)

As a consequence of repeated unhelpful answers from health care professionals, three families pursued options outside of the public health care system, with two families accessing a private psychologist, and one family accessing a combination of a private psychologist and alternative health care (i.e., biofeedback). Although these parents initially pursued a private psychologist to help their children with AS, they often found themselves becoming the primary participants in therapy. Parents described how their children were uncooperative in, and resistant to, therapy sessions, creating an unpleasant experience. As a result, parents continued to attend the therapy sessions by themselves in the hope of finding the answers they needed to effectively manage their children with AS.

Father: Whenever we got [Daughter with AS] in there to sit with us, which I think was only once or twice, she was incredibly abusive to the psychologist, and it brought out more anger against us for forcing her to do this. (Family 7)

While the private psychologist was helpful for one couple in shedding new light on their challenges and helping them figure out how to manage the tension in their family, the private psychologist was not as helpful for the other two couples who cited a reticence to diagnose and inability to proactively offer solution strategies for help.

Mother: This [Private psychologist] was looking at Asperger's, but didn't like to diagnose because she didn't want to label them, and then it's like 'Oh, you're pinned to that label,' and maybe that's not what he has, maybe it's Pervasive Developmental Disorder-Not Otherwise Specified or something else but that's what she was looking at. (Family 8)

Father: [Wife] and I would go to [private psychologist] together, and we'd sit there and talk about things, and I just felt like it was a waste of time, no one ever seemed to be making recommendations or taking steps to do anything. (Family 7)

For the one family who pursued alternative health care, biofeedback was noted to be helpful in teaching their daughter how to self-regulate challenging emotions (e.g., anger and anxiety).

In pursuing options outside of the public health care system, families experienced a significant amount of financial, familial, and psychological stress. The financial stress of pursuing options outside of the public health care system was high, costing one family \$12,000 a year to enrol their child in various services and supports. One mother explained how this financial stress had a negative impact on her marital relationship:

There's extra financial pressure because he needs this service that costs 700 dollars a month but because you don't have a diagnosis you don't get the funds, so that's coming out of pocket. We had a year where we had spent over \$12,000 on medical expenses for [Child with AS], on therapy and stuff, before diagnosis. That stuff affects you (laughs), that affects your marriage, it has to. I think when we think it doesn't that we're being pretty foolish. (Family 3)

As parents spent increasing amounts of time, energy, and resources on their children with AS, relationships with 'typically developing' children, and between parents, suffered.

Mother: (Child with AS) was just consuming everything, right, and there was no time for us to hang out with [Daughter] or to hang out with [Youngest Child] 'cause [Child with AS] just consumed every minute of every day with something and so our marriage was feeling that pressure and we knew, okay, this is a breaking point for us, like we either have to figure this out or we're in trouble. (Family 3)

Father: I can't imagine what it would be like to be [Youngest Daughter] because really, when I think about it, every waking moment of our days was just spent with [Eldest Daughter with Asperger's] on our mind, and [Youngest Daughter] had to be able to sense that or feel that. (Family 7)

In a few families, the 'typically developing' children became so frustrated with their sibling's unpredictable, and sometimes violent behaviours, and the consistent inability for the family to spend quality time together, that they disengaged from the family and pursued their own interests.

Mother: [Child with AS] can't do crowds, sometimes even being in a line up at movies is an issue, so it really restricts what we can do as a family and causes a huge amount of frustration for his brother and sister, which causes more disengagement 'cause then they just go off on their own with their friends to do their own thing because they're just tired of it just not working anymore, and going anywhere, doing anything as a family isn't just

the sibling rivalry, the little bit of bickering, it can become a huge issue and quite violent, and so it's very tough to manage that. (Family 6)

Without an accurate answer to their difficulties, parents were unable to find effective ways to parent their children with AS. The parental blame, unhelpful answers from school and health professionals, and worsening problems with their children all served to 'unbalance' parents. Parents became worn down by the problems without any forthcoming or foreseeable answers, and they began to flounder.

For 2 mothers and 1 father, the psychological stress of parenting without any helpful answers culminated in depression, which required either continued psychotherapy or anti-depressant medication as treatment modalities.

Mother: [Husband] has found it extremely frustrating, not getting any answers, and trying to get control of the situation, and I think that's caused a fair amount of depression just because when a person who has that personality where they need to be in control to feel confident with what's happening, when you can't get access to those resources and you keep hitting a cement wall, you start to feel like you're losing control of the situation, and depression sets in. (Family 6)

Mother: First born perfectionists like I am are intense, and so whenever things happen you take them upon yourself, it just is a psychological stress that is really difficult sometimes to deal with, and that's where the depression comes in and the medication. (Family 1)

Overall, in the process of seeking help, all families, with one exception, experienced unhelpful answers from professionals, which increased parental frustration and desperation and contributed to the process of 'losing their footing.' In their efforts to regain their footing, most parents continued to move forward, hoping that perseverance would lead them in the right direction to help their children and improve their family functioning. This experience of persevering through the problems will be presented and discussed next.

Persevering Through the Problems

Five families were able to reach the diagnosis of AS through perseverance. These families persevered through: 1) reading books on child development; 2) having discussions with other parents and friends who had children with AS; and 3) seeking out professionals who could recognize AS.

Through reading books on child development, one mother discovered AS and found the list of symptoms to be an accurate summation of her child's differences.

Mother: Every time that I read about Asperger's I was just sure, you know. Father: You did your homework, you read tons, you checked out books from libraries, and got articles on the Internet. You researched it really well and you said "That's it." (Family 5)

Two mothers engaged in discussions about their children with friends and other parents of children with autism/AS. Through these discussions, the mothers were informed about AS, and received helpful recommendations on what to do to reach the diagnosis.

Mother: The Moms [at the support group for parents of children with autism] said "Your son has Asperger's, without a doubt," and I went, "What's that?" and the Mom said, "I have a 13 year old son who has been diagnosed with Asperger's, and what you're talking about right now was him last year," and she's like "It's not gonna get better, it only gets worse unless you can do something," and she's like "Unfortunately, it's very hard to do something without having that name and having that recognition." So, as a group, they encouraged me to just go home and journal, to write down things that were weird, that didn't make any sense. (Family 3)

Mother: I heard about AS through someone in one of my classes, and someone else had mentioned "Have you heard of this?" and I said "No, what's that?" and they said "Oh, my friend's son has it," and I think they were trying to plant a seed in my mind, and it was good because it did...and it sort of sparked something, and when I looked up more stuff on it I thought yeah, 95 per cent of this actually does fit" (Family 4)

These families not only found a plausible explanation for their children's differences but they gained the confidence to return to professionals, and actively pursue, and advocate for, the diagnosis of AS for their children.

Mother: We finally ended up going back to the paediatrician and just saying “You know what, help! This is what I think it is [referring to AS],” and I went back with my list, and my sheets, you know, the dentist asked him this, and this was his response...and as we started to look at that stuff we were like “Whoa, how did we miss all this?” (Family 3)

Mother: When we went back to Dr. [Child and Youth Psychiatrist] he was like “Yeah, let’s get the ball rolling on this,” and from that moment until we got the official diagnosis was a year, but for that whole year we pretty much knew, and we just needed the diagnosis. (Family 4)

Mother: We just did the best we could until it just became more obvious that there was more going on, and the more I read about Asperger’s as time went on I decided that we should talk to Dr. [Child and Youth Psychiatrist] again and retest. (Family 5)

In addition to the three families who obtained the diagnosis through reading books and having discussions with friends, two families obtained the diagnosis of AS after an experienced teacher at school recognized their child’s problems.

Mother: Well, the teacher said “There’s something just not quite right,” and she said “I don’t think it’s Attention Deficit but maybe the Doctor has some other ideas, it’s something that could be in the autism spectrum...and we got referred to [autism assessment center] where we got the diagnosis. (Family 2)

Mother: Until you can get a proper teacher who’s gonna recognize [AS], you’re basically out of ‘luck’ too because the assessment forms you have to send in, the teacher gets the one set of forms and parents get the other set of forms, and if they don’t agree then nothing...and Mrs. X [teacher] recognized Asperger’s and her assessment just about agreed with ours identically, and yet the grade 3 teacher’s didn’t because she had, I think, so many other problems in the class and he did his homework, he wasn’t a nuisance, wasn’t a problem, that it was just bypassed. (Family 8)

For these parents, giving up was not an option as they persevered, maintaining a resolute hopefulness that they would find the answers they needed to help their children, and restore their confidence in parenting.

Mother: What choice do you have, you can’t give up, right, consider the options, it’s like, what, leave? [laughs] you know. Okay, well if you’re not willing to do that and you can’t, you know, rather than give up you just have to keep trying if you want a better quality of life, and dealing with the situation, you just have to keep trying, it’s all you can do. (Family 5)

Overall, through perseverance, these families were able to reach the diagnosis of AS. This was not the case for other families, however, who experienced crisis points before they were able to reach the diagnosis of AS for their child, which will be discussed next.

Crisis Points

For two families, the problems became so bad that they experienced crises, which included violent episodes at school, hospitalizations for psychotic episodes, and suicide attempts. This was a “critical point” in these parents’ lives where they were “falling apart,” reaching a point where they did not believe they could continue to parent. As one father stated, “I think at that point, another 6 months of no answers, and [Wife] and I would’ve been done [referring to integrity of marital relationship].” Only through an emergency hospitalization was the child able to be assessed by new professionals with specialized knowledge of the autism spectrum, which eventually led to the diagnosis of AS.

When their children were hospitalized, parents experienced mixed responses ranging from relief to helplessness. Although relieved to finally have a break from the emotional demands of managing their children with AS, parents described also feeling helpless in not being able to stay with, and help, their children. These parents had to relinquish their parental need to protect, and trust professionals with their children.

Mother: In the adolescent psychiatric ward, you have to leave every night, you have no choice and they lock the doors behind you, so it’s like prison, so emotionally, going, “Oh I can’t stay, and I can’t help [begins to cry], sorry [4 second pause], and [Child with AS] standing there crying [4 second pause]. It was hard to leave him [5 second pause] but coming home and [Child with AS] not being here for that month [5 second pause], it was different, it was kind of nice. Father: I was wondering what a normal family feels like. (Family 6)

These crisis points marked times when parents could not cope any longer as they came to the realization that they could not help their children. The parents had maximized all options for

help, and the problems continued to worsen. As a result, some parents considered leaving the family.

Mother: [Husband] was very much at a point where “I’m gonna have to give up, I cannot do this anymore, I can’t cope with this child and I don’t know what to do, and the system’s not helping us, so maybe it is us.” (Family 6)

Father: Yeah, that’s all I give myself credit for is being stubborn enough to not give in, and to stick around even though it was tempting at times. At times I felt like walking out the door. (Family 7)

An alternative answer to their overwhelming distress was to give their child up.

Mother: I think by grade 6 there were some days where we talked about it, there’s something wrong with this child and we don’t know what to do, and we have to give him up, and I think that’s when we reached the crisis point and we didn’t know how to help him anymore. (Family 6)

Mother: That last time she was in the hospital after overdosing on Tylenol and she was so miserable, didn’t want to come home, crying, and afterwards I thought if she’s that miserable, this was about the 4th time she was hospitalized, I just have to let her go, I have to let her do it. (Family 7)

Although the integrity of the family system was threatened by the crisis points, these two families remained together. Some parents credited their strong marital relationship and ability to support each other during difficult times to be key factors in their ability to cope and keep their marriage and family together.

Mother: I think the only way that we have coped, and certainly there has been no structure with any system to help support us in any way, and no family support emotionally available to support us, not even to babysit our kids. Our only support has been each other. (Family 6)

Mother: We were pretty united most of the time, and I think we had a pretty strong relationship, so if we were any less strong, I think we have an exceptional relationship, and if we were close to on the rocks, like, if there had been any pre-existing instability, there’s just no way [we would have made it]. (Family 7)

Other parents credited their professional success with helping them survive the crises and find their way through the system to obtain the diagnosis of AS for their children.

Mother: We've been really lucky because we barely made it through some of those crises and I don't know how we did, but I look at other people who aren't as successful in their life, and how do they cope when they're trying to deal with other family issues, or a parent who is sick, or one of them is not working, or they're at a different economic level, or they're a single parent. I can't even begin to imagine how they cope with a system that didn't identify [the AS]. (Family 6)

For both families, the mothers were able to carry the emotional burden for their husbands during these crisis points, spending the time, energy and resources to find the help they needed.

Mother: That's where I said "I cannot give up this child," and [husband] said "Well, you'll have to choose between him and me 'cause I can't cope anymore," and that was fair enough for him to express his feelings that he was at a breaking point and I said at that stage, "My choice is to give up neither. I will figure this out," and that's where I started making phone calls and just randomly phoning psychologists to say, "Can you recommend a psychologist that can work with this type of a situation?" until I found one. And then that's where I said "Okay, you and I, there is a solution, and I don't know how long it's gonna take but we're gonna figure it out," so I tried to take the emotional burden off of him. (Family 6)

Father: Every spare minute was spent researching, going to counselling, trying to get help for [Eldest Daughter with AS], and finding out what could be done. [Wife] paid a far higher price with her personal time than I did. I was confrontational with [Eldest Daughter with AS] and tried to be hard-nosed with her, which she now says she really appreciates but I don't think I put as much into it as [Wife] did. What I did is just, I stood up to her. [Wife] would spend hours of her time researching, and trying to find help, and trying to solve the problem talking with people. (Family 7)

The mothers helped support the fathers during the crises, pushing forward to receive the help they needed. During these difficult times, both families relied on more specialized assessments from a multidisciplinary team of professionals to receive the accurate diagnosis of AS.

In this section the process of 'losing one's footing' as a parent was presented. This was an uneasy time in most parents' experiences as they ran into myriad problems with their children at home and at school, encountered parental blame, received unhelpful answers from professionals, and ran into dead-ends and even crisis points. Parents became frustrated with a system that was not forthcoming with helpful answers, puzzled by the reason for their children's differences, and uncertain and exhausted in their ability to effectively parent. When parents

became challenged in their ability to feel confident and desperate in their ability to effectively parent, they began to lose their footing. However, when parents obtained their children's diagnosis of AS, they were pointed in the 'right' direction as they now had a name that oriented them to their children's differences, and they could better understand, accept, and manage their children's behaviours. Further, the diagnosis enabled them to begin to let go of self-blame and dismiss the idea that they were at fault and "bad" parents. As a result, parents were able to restore their confidence in themselves as parents, and begin the process of regaining their balance, which will be discussed in the following section.

Regaining Our Balance

The process of 'regaining our balance' occurred as parents acknowledged, gained understanding of, and moved towards accepting, the AS, and the full extent of its influence in the family. This was a time when parents learned about the AS, made a place for it in the context of their family lives, and developed strategies to restore balance. The first part of 'regaining our balance' involves 'finally finding a name,' which will present parents' responses to receiving their child's diagnosis of AS. The second part of 'regaining our balance' encompasses the process of becoming experts on their child and the AS, detailing how parents balance multiple and varied tensions and develop strategies to effectively manage AS in the context of family life.

Finally Finding a Name

Many parents anticipated the diagnosis of AS as they were familiar with the condition through their readings, academic work, and discussions with others, and had a 'hunch' that it was the reason for their children's differences. Thus, when these parents met with professionals, they expected and looked forward to confirmation of this diagnosis.

Mother: Once the counsellor said that he possibly had [AS] and I looked at the materials, I thought that is him to a tee, and that's exactly what my husband thought too. I would

say about 75% certain that he had that. And of course there are always some things that some children won't have that some others might have so I figured that 75% was a pretty good thing, and I thought yeah, this is it. And I just expected a confirmation. (Family 1)

Indeed, parents experienced the diagnosis as “good news.” This contrasts with the assumption of some professionals that the parents would be sad and tearful.

Mother: When we went to get the results she said to me “I have some bad news for you, he has Asperger's Syndrome,” and I said “It's not bad news because he has it, whether you tell us or not, but now we know what we're dealing with.” (Family 2)

Mother: The psychiatrist and psychologist sat us down and pushed the tissue box into the middle of the coffee table, and very gently...when they said it we were like “Wooh, yeah, good, okay!” and they're like “Oh, so you're okay with this?” and we said “If you would've told us that he didn't have Asperger's we would've been floored and surprised.” (Family 4)

This experience of mismatched expectations further solidified some parents' belief that health care professionals did not understand or appreciate how hard they worked to get the diagnosis, and how difficult life had been without a way of making sense of their children's behaviours.

Parents described how the diagnosis elicited a feeling of relief as they were finally able to make sense of their children's differences.

Mother: It was a big relief, it took a lot of stress off because it was like all of a sudden, all these things, like why can't he do, why, and those questions were answered. (Family 2)

Further, the diagnosis legitimized and affirmed parents' experiences as real, serving to assuage some of the guilt around being labelled a “bad” parent.

Mother: When the formal diagnosis came there was a huge amount of relief for both [Husband] and I, and I know very much so for him, I mean, that's where he talks about not expressing his emotions, and internalizing them instead. At that particular point, I think he did have some tears out of the pure relief to say “Wow, somebody finally acknowledged that this is real, we're not crazy parents. This is real. And it's hard,” and somebody in the world acknowledges it [laughs], you know, huge relief. (Family 6)

Mother: The [Child and Youth Psychiatrist] said to me “What difference is the diagnosis gonna make?” and I said “It's just that, then at least I will know okay, it's not my bad parenting skills [laughs], there is actually something that [Child with AS] has in him,”

and I don't want to say "wrong" with him, but the little things that we notice or think that aren't right, we are actually right, you know. (Family 8)

Thus, the diagnosis aided in dissolving and deflecting some of the blame parents experienced from others who questioned the validity of the diagnosis and doubted parental competence.

Mother: [Extended Family] would say "Well he looks normal and he acts normal, and he's really smart, so I don't understand this Asperger's, or I don't really believe it." As parents we're able to brush that off now because we can say "It is real," and whether other people accept it or not doesn't matter 'cause we're not taking it on anymore, we're not taking on the blame anymore, and we're not gonna feel guilty about it anymore." (Family 6)

Father: [Reaching the diagnosis of AS] was such a big relief, it took a huge weight off of my shoulders to know that okay, I haven't done anything wrong or, you know, at least I haven't screwed up too badly because, I mean, we all screw up as parents, I don't ever delude myself to think I've always done the right thing by my kids, but yeah, it was a big relief. (Family 7)

With the diagnosis, parents were able to better understand their children, which eased some of the challenges of parenting.

Mother: When I started to read up and get more informed on it, so much made sense all of the sudden of why he did and said the things he did, and felt the way he did, and it made our home life easier because now we know, it wasn't just like "Why can't you be like other kids?" and "Why are you doing these things?" It was like "Oh, okay, this is why." (Family 2)

Mother: [With the diagnosis] we know exactly what we're dealing with, we're not dealing with, "Oh she just has anxiety," you can say, "It's because of this," and you can read about it and learn about it and you can find out what you can do to help. (Family 5)

Thus, the diagnosis was freeing to parents as they could now accept what could not be changed rather than always feeling compelled to change their children's behaviours.

Mother: With the diagnosis we were able to accept her behaviour, and not bad behaviour, you know, we had kinda given up trying to change it by that time anyway, but at least there was a reason for it that we could try to understand her instead of trying to change it. (Family 7)

Father: I immediately had 100 per cent tolerance for what [Child with AS] was exhibiting and behaviour and what-not, and all of a sudden it seemed like you could tell what was really true in her and what wasn't, like sometimes you could tell that she was doing

something to just manipulate me, and then I wouldn't tolerate that, but you could tell when you were being manipulated and when it was really her condition that was showing. (Family 7)

The diagnosis was also freeing in that parents not only gained a greater acceptance of their children but of their own ability to parent, thus gradually restoring and reinstating their confidence as they regained their balance.

Mother: The diagnosis helps because you stop blaming other people, you accept that this is the way he was born, and that is okay. And it's nobody's fault anymore. And no parent is perfect, and we've done the very best that we can, and it's okay, that's huge. (Family 6)

While all parents described feelings of relief in finally receiving the AS diagnosis for their child, a few described co-occurring responses such as regret that their child was not diagnosed earlier, anxiety about the future for their child, sadness over how the condition would affect the life of their child, and anger at the unfairness of the parenting burden associated with raising a child with a difference of ability. Thus, parents' responses to receiving their child's diagnosis were not limited to relief and celebration but also encompassed a complex array of challenging emotions.

Parents experienced the diagnosis as a "light at the end of the tunnel" as it pointed them in the right direction of where to go to help their children. The diagnosis was the key that unlocked the door to a wide range of services and supports.

Mother: By putting a name on it, there's a lot more help available to you, without the name there's less help, as far as the school system goes, you don't get help with the CEA without a diagnosis of autism. (Family 5)

Some parents were surprised by the help that was available, particularly after experiencing so many years of managing alone.

Mother: She handed me this folder and said "Okay, here's this and this, and now you have access to all this" and I said "What is all this?" and she said "He's autistic, he can have all this stuff. He can go to all these programs" and I said "But, I didn't even know

these existed... We just didn't even know any of this existed, it was like all behind this closed door that nobody knew about." (Family 6)

Other parents struggled to orient themselves to the services and supports available. Two mothers explained it this way:

Everything's so new [with diagnosis of AS], and where do we go from here? Like where do I start? That was a big thing, like where do I start here, there's so much information and what's the best thing to do here and where do I go? Once you get started on a program and stuff, a lot of it is hit and miss. (Family 2)

I don't know everything that's out there because it's not like all of a sudden all of these people contact you and say "Okay, you could do this and you could do that, and you could do that" and that's where I find part of the problem is well, "What do we do? What kinds of programs should we access? What kinds of things should we do?" (Family 5)

In not knowing the most effective services and supports to access for their child, parents decided to take on the role of researcher, actively seeking out the information they needed to make decisions about what would be most helpful for their child. Two mothers described how they claimed the primary role of researching, managing, and organizing their child's services and supports, noting how they often passed on salient bits of information, and elicited their husbands' perspectives on services and supports, on an 'as needed' basis.

Mother: I find the majority of fathers, they're not so much the reader of all the material. Often the mother gets really involved, they're very protective of their child so they read through everything and they either sit down and discuss it with their husband or they just do a lot of it on their own...In my case, I go out of my way and do all the research 'cause I know that's really tough for [husband] to read. He's better if I send things on the Internet rather than reading through all the documents. (Family 6)

Mother: I probably do most of the research part of it, and kind of this is where I think we should go with this therapy or that therapy, and [Husband] usually agrees, it's not that he's not involved. When I say "Oh, I think he'd really enjoy this horseback riding program that they offer here, what do you think?" He would go "Okay," you know, but at the same time, if I can't make it to pick him up from horseback riding, my husband's right there, so it's not like I'm single parenting him but at the same time he's not quite as 'hands-on' in some ways, and I think that that's probably pretty common. (Family 3)

Overall, obtaining the diagnosis of AS for their child was a pivotal point in these parents' lives. The AS diagnosis helped parents in the following ways: 1) opened up understanding of their child, which enabled acceptance; 2) affirmed parents' experiences as real, which helped diminish parental blame; and 3) opened up the door to services and supports, which helped their child and themselves manage the AS. However, in addition to the relief and celebratory responses to the diagnosis, parents also experienced challenging emotions such as regret, sadness, and worry, and some initially struggled with navigating the wide range of services and supports available. Thus, although the diagnosis was largely experienced as "good news" for parents, it did not immediately restore balance. As parents became experts on their child and the AS, developed and strengthened strategies to help balance for their child, themselves, and their family, and learned how to navigate the services and supports, they began to feel comfortable and confident in their ability to parent and were able to move towards regaining their balance. This process of becoming experts will be discussed in the following section.

Becoming Experts on their Child and the AS

As parents learned about the AS, they gained an enhanced understanding of their children's differences, and gained knowledge and skill in separating their child from the AS. This was a key step in the process of becoming experts on their children and the AS, assisting parents in balancing multiple tensions and developing myriad strategies to help support their parenting success, which will be discussed next.

Separating the child from the AS.

As parents gained a greater understanding of AS, they were better able to read their children, determining whether the behaviours they were seeing were AS-related or child-related. A few parents conveyed their uncertainty in managing this tension of separating the child from

the AS, wondering if they were correctly reading their children's behaviours and responding appropriately. As one mother explained, "We often say to each other: Is this an 'Aspie' [affectionate term for person with AS] thing or is it him being a defiant, 11 year old boy?" This was not a straightforward or easy process as parents worked hard to perceptively 'pick up' and accurately interpret their children's sometimes subtle behavioural cues.

Mother: Knowing that some of the behaviour we see is Asperger's and some of it is that 12 year old boy, that's going through hormonal stuff, and how to separate those two things, that's a new walk for us. It's something we haven't done before. We can't rely on what we already know because we don't know anything. (Family 3)

With time, parents gained greater expertise in understanding and reading their children's behaviours. One mother explained it this way:

Sometimes [Child with AS] chooses to wear shorts, but quite often there's something that's happened or something that's coming up that may be causing a little bit more anxiety. So, because he's dealing with that he's less able to deal with the other stuff. It's almost like he has to trade off stuff...He still has to go to school so that can't go, but he can choose how his feet feel...and whether he's gonna be hot or not and choose to leave his jacket at home, so we look at those things as signs and not necessarily behaviour. It's not defiance. He's not necessarily choosing to not wear socks as much as it is that he really can't today. So sometimes he chooses, I'm not naive and I think that he's still a 12 year old boy and tests that, and I think me and his Dad have a pretty good handle on the difference at this point in the game. (Family 3)

By gaining this expertise in reading their child, parents were better able to understand the most effective approach they needed to take to manage their children's behaviours, and organize their day.

Father: We know when to read him, when he's on or when he's off, and we structure our days around how to deal with him or how he presents himself...if he gets up and he doesn't say anything, and he just sits there and stares off into the TV, you know, it's an off day. If he gets up and he sits down, and he's staring off at the TV, and you ask him a question and he responds very politely, you know he's going to have a great day. (Family 6)

Further, with increasing expertise in the ability to read their children, parents began to see the world through their children's eyes, and could intuitively sense his/her needs.

Mother: It's almost like a second sight into his world, you know, like, 'cause I'm with him so much that I start to see things like he does, you know, and what he's thinking without even asking [laughs] a lot of the times. (Family 2)

As parents were able to "get inside [their] children's head" and gain "second sight" into their children's world, they had the opportunity to consider the AS and its influence separately from the child. In reading their children with increasing accuracy, parents were able to gain understanding about what behaviours were under their children's control and therefore modifiable, and what behaviours were under the control of the AS and therefore not modifiable, or only modifiable with great difficulty. As one mother stated,

I am so much aware of how much Asperger's is a part of our son in that for [child] sometimes it's not his choice, sometimes it just takes over, sometimes we can see his frustration with it too like, "Mom I just need to watch this movie," "Honey, you can't" "But Mom, I just need to!" And he, as much as us, doesn't want to watch the movie (laughs). (Family 3)

Through learning to read their children with increasing accuracy, parents gained a balanced perspective of their children's needs and abilities, which supported the process of adjusting expectations.

Adjusting expectations.

As parents carefully read their children and gained expertise in separating the child from the AS, they could better determine their children's capabilities and the parental response and approach required. Some parents became flexible in their expectations for their children, as they began to recognize that some behaviours were a reflection of the AS, and thus were not under their children's control.

Mother: A lot of his idiosyncrasies, once we found out he had Asperger's, immediately we let it go. If he wants to act like that let him. That's the way he is, leave it be. Because Asperger's children, they grow up with idiosyncrasies, you know, like he'd be flicking his fingers, you know, that kinda stuff, but as soon as we found out he had Asperger's, whatever. Didn't matter. (Family 1)

However, other parents had difficulty with separating the child from the AS, experiencing uncertainty in knowing how much power and influence to give the AS. As a result, they were reticent to adjust their expectations according to their children's needs and abilities, and always accommodate or make allowances for the AS.

Father: I was reluctant to always want to pull out Asperger's Syndrome every time something came up and say "Well, he has Asperger's..." It's like, you can't just keep saying that, sometimes he has to learn how to adapt to live a certain way, you can't just keep pulling out the Asperger's thing but there were times where I was not acknowledging fully that actually, yeah, that is Asperger's, and that is the way that works, and that is the way he is going to be, and it's not going to be this other little boy you think he should be. (Family 4)

Mother: I guess, whether it's Asperger's or teenage stuff, but he is a little bit rude, and a little bit lippy, he gets in a bad mood some days, like "No, I'm not doing that!" and I'm like "Yeah, you are doing that. That's a part of what makes our family run or makes a household run, and everyone has a share in it, so that's the way it goes." (Family 8)

Overall, this experience of reading the child and adjusting expectations accordingly was indeterminate and fraught with tension as parents grappled with understanding what behaviour was under the control of their children and what behaviour was under the control of the AS. Parents had to acknowledge, understand, and make space for the AS to effectively work with their expectations and manage their children's behaviour.

Parents found they often had to remind each other and their typical children of the AS, and the need to adjust their expectations according to the needs and abilities of the child with AS. In this case, the mothers were the ones who most often intervened, explaining their children's behavioural cues and triggers to family members (e.g., spouses, typical children) to avoid escalating their children with AS and manage parenting and family life with greater ease.

Father: I'd say one other thing, in my case, is my wife's reminders to me to remember that he has Asperger's and to remember that what might seem like inappropriate behaviour or wrong behaviour is actually expected for him. (Family 4)

Mother: A lot of times I'm explaining to my husband and my [typical child] too, you know, "While he didn't mean to do it or he didn't..." and so I'm explaining to them and that can be frustrating 'cause they just don't get it, and I think "How many years have you been around him?" (Family 2)

Although frustrating and challenging work, some parents found the process of adapting their parental approach and reminding each other to adjust their expectations contributed to self-growth as well:

Mother: Asperger's kids can't read social cues they can't read emotions, they can only read you to a point...and so I think we really adapted too by calling each other and saying "Hey, that's not gonna work for [Child with AS]," and it's been hard on us but it's also made us grow quite a bit. (Family 6)

As parents confronted the reality of their children having AS, and adjusted their expectations for their children and the AS, they described a process of grieving. These parents grieved for the loss of idealized goals and expectations for the 'normal' child.

Mother: Our goals changed from [Child with AS] having friendships to [Child with AS] developing one true friend, and that he understands what that means to be a friend. So those expectations change but in that changing there's a part of you that has to let that expectation go, and that's not always an easy place to go as a parent. When you're pregnant, and you have hopes and dreams and desires for your kids, and then the realization that not all of those things are gonna be possible, is hard when you first get that. (Family 3)

Father: I think you're always going to, if you're not normal, then there's always gonna be, I guess a bit of a grieving, 'cause then you have to let that go, your expectations of normal. (Family 1)

Some parents noted how they would be continually disappointed by unmet expectations if they could not accept the AS and adjust their expectations accordingly.

Mother: I think that that's a real frustration with parents is that they want their kids to be, I mean you want your kids to fit in but you have to accept that they're not gonna be like other kids and if you don't you're just gonna frustrate yourself and make yourself go crazy over it, you know, you just have to accept that. (Family 2)

Mother: The expectations have to change because his abilities aren't the same, you know, if he was in a wheelchair I still wouldn't expect him to run in a marathon, right, so my

expectations would change for that and they have changed because of Asperger's.
(Family 3)

As parents adjusted expectations for their children and the AS, they had to balance relationships with their 'typical' children. In adjusting their expectations for their children with AS, parents had to respond in a fair manner to their typical children who were often younger than their sibling with AS by several years and who had difficulty understanding why these allowances were being made for their sibling. Parents noted how the abilities of their typical children exceeded the abilities of their children with AS, and, as a result, they held higher expectations for their typical children. This incongruity of expectations between children drew forth a sense of unfairness that parents had to manage. One mother explained it this way:

It requires different expectations, not only for one child but for all of ours at times, which can get a little bit challenging 'cause [typical child]'s expectations and [child with AS]'s expectations right now really are the same even though he's 3 years older than her so it's explaining to [daughter] that you know "He might have to do the same chores as you but it's because he can't do more," and explaining to her that it has really nothing to do with, we tell [typical child] all the time it has nothing to do with being fair it's just about what you can do. (Family 3)

In addition to balancing their expectations, parents helped others (i.e., school professionals, strangers, and extended family) balance expectations for their children. Some parents unveiled the AS to school professionals to encourage understanding, acceptance, and adjustment of expectations for their children. One mother drew upon the metaphor of a 'tightrope walker' to interpret her child to school professionals, helping them separate the child from the AS, gain understanding and acceptance of the child, and adjust expectations according to the child's needs and abilities.

Mother: There are times when I'm going to the school and my goal is that they get the Asperger's...and teachers need to get that, like this is what happens: Stand on a tightrope, let someone shut the lights off on you and then something's gonna start beeping, and now walk across the line, and they would look at me and go "I can't do that," "Okay, in the same way he can't do what you're asking him to do because that's how it feels to him

when you put him in a classroom with a kid tapping a pencil beside him and the lights flickering and the hundred people touching him. (Family 3)

One mother explained that when the school was able to understand her child's AS they were better able to adjust their approach, teaching their child from a place of acceptance and understanding rather than judgment and unrealistic expectations. As this mother noted, when teachers understand her child's AS and how it factors into the teaching and learning experience, they "tend to be a little bit more gracious, and they tend to change the way they teach or the way they approach something."

However, many parents described how some teachers continued to hold unrealistic expectations for their children, expecting their children to manage homework and hand in assignments on time without frequent reminders. This was upsetting for parents, as noted in the following quote:

Mother: I had one teacher tell me "Well, he's twelve years old, he should be able to do this now," and I said "Hence the title 'special needs.'" You know, [Child with AS] was supposed to write in his journal every day, and [teacher] was to make some comment in there, and she wasn't writing in, and I said "Well, why isn't this being done?" and she said "Well, he doesn't bring me his journal," and I said "Well, you know, could you not ask him for it?" and she said "Well, by the time you're twelve I figure they should be able to do this," and I told the principal, I called a meeting for the head of special needs, and I said, you know, I went home in tears that day cause I thought, I am so frustrated, you know, how many years I've been explaining this and then to have somebody say that to me. (Family 2)

Parents found they had advocate for their children within the school, educating professionals about AS, encouraging understanding and acceptance, and prompting an adjustment of expectations to meet their children's needs and abilities.

Mother: Sometimes you get teachers who just won't go there, they just refuse and it can be really frustrating, that's when I've had to go to people above their heads, because they're dealing with his life and if they're telling him they're gonna do one thing and they don't do it, or if they're treating him unfairly because of his differences then I just won't put up with it, and I would expect that of any kid, you have to make adjustments, and I've

had teachers say “I’m not gonna do that.” Well, then we better find another teacher who is willing to. (Family 2)

Parents also helped strangers work with their expectations. This occurred when parents encountered judgmental remarks from strangers during public outings.

Mother: There’s always somebody, “Why’s he touching all the oranges?” “It’s just what he does. Wash your fruit and vegetables. Ha ha, have you learned your lesson now?” (laughs)... Sometimes that’s frustrating, sometimes those are the things I laugh at ‘cause I think, for heaven’s sakes, you have nothing better to do than stand in the vegetable aisle and pick apart how many times someone touches a piece of fruit, and sometimes I don’t have the patience for it. If we’ve had a rough day or a rough week, and I’d rather be anywhere else, and someone makes some obscene comment like that, those are the ones that I kinda turn and go “you know what, he’s autistic. I’m sorry he’s not meeting your expectations” (laughs), and usually they go “Oh!” and they just kinda walk away. (Family 3)

Sometimes the work associated with adjusting expectations extended to family members as well.

Mother: It’s more family that goes “Why is he doing that?” When we were over for dinner and [Child with AS] was sitting at the table going [simulates a vigorous sniffing noise] 20 times, and [Husband]’s Mom is like “Stop it! That’s disgusting!” and I’m like “No, he can’t!”...and “Oh, it sounds just rude,” “Well, it’s what he’s doing, he just does it, he can’t stop it. You can point it out and it’s gonna last for an hour, just ignore it.” (Family 3)

Mother: I remember writing my Dad a long email telling him, explaining this is what it is and then saying to him, “You need to read up on this because he’s your grandchild,” and my Dad’s a really nice guy but he was sort of acting like “Well, he should just be able to shape up, pull up by the bootstraps, straighten your tie and chin out, and pull through kind of thing. Nice that he has this Asperger’s thing, whatever that is, but get some medication, let’s go,” and now I think he really understands a lot more, and I know that he did his own research when I asked him to. (Family 4)

Thus, even with the diagnosis of AS, parents found themselves explaining and reminding extended family of the implications of their children’s AS, and the need for acceptance and an adjustment of expectations to accommodate the AS. Parents became disappointed in their extended family when they refused to make the effort to understand or accept the AS, and held

firmly to their fixed beliefs and expectations for 'proper' child behaviour. Two mothers explained their disappointment this way:

Mother: My parents won't accept his autism, and people who know [child with AS] have said to me, you know, "[Your parents] are just missing out on so much. He's such a neat kid, and if they only took the time to realize that, and get to know him," and that's true, you know [in sad tone]. (Family 2)

Mother: My Dad, he just refuses to even try and get it, and that is frustrating because I think he's someone that's gonna miss out in the end, like he's gonna miss out on the quirky things that make [Child with AS] [Child with AS] 'cause he's not willing to see them and he's not willing to accept them. (Family 3)

Many families attributed the reason for extended family not understanding or adjusting their expectations to the invisible nature of the condition. In not being readily visible, many extended family members believed the child was a behavioural problem and therefore they held firm with their expectations. Some families experienced such frustration from extended family not wanting to adjust their expectations that they felt isolated from their extended family and unable to connect with them for social support. One mother explained it this way:

Even if you have a very strong support structure in family members, you can't really call on that because when you have a child who has a social disability it's not visually there in a sense so they don't always understand, they don't see that something's wrong, they just think well, your child's just a pain to have around, he doesn't understand, he doesn't listen, he's always causing trouble. So you can't ask for that support structure because they just don't understand. (Family 6)

Further, parents suggested that not only extended family but others in the community expect a child with AS to behave in readily recognizable and physically demonstrable ways such as lack of speech, repetitive rocking behaviours, and refusal to make eye contact. As a result of this misconception surrounding AS, parents explained their difficulty in getting others to adjust their expectations to accommodate the AS.

Mother: Asperger's is not an autistic child sitting with a helmet on his head rocking back and forth. It's someone who looks just like you and I, and this is the way they present, it could be a he or a she, he could be handsome and attractive and look normal, just like you

and I. But they can't read your face. They're blind. They don't know that you're mad. They don't know that they're standing too close to you. (Family 6)

Mother: People have an image of autism and Asperger's, of some child sitting in a corner rocking and they can't talk and they don't want to be touched and all this, and [Child with AS] was so different from that that it was hard for people to accept that that's what was wrong with him. (Family 2)

Overall, adjusting expectations was challenging work for parents as they struggled to balance their own and others' expectations of what was reasonable and unreasonable in light of the AS. In the process of adjusting their own and others' expectations for their child's behaviour, parents also managed their emotions and the emotions of their child, which will be discussed next.

Managing emotions.

In the process of separating the child and the AS, adjusting their expectations for their children's behaviour, and experimenting with different approaches to difficulties, parents struggled to manage and shift their emotional responses to problematic behaviours. There continued to be times when parental limits for acceptable behaviour were challenged, and they became frustrated and angry with their children. During these times, parents struggled to step back from the situation, reflecting upon and reminding themselves of their children's condition, and the need to accommodate the AS.

Mother: But even if he does say something that's inappropriate and how you respond, like you can tell him in a nice way that that's not appropriate rather than getting upset about it, so even that's an ongoing thing because I get frustrated with him still all the time and I still have to step back and think about what I'm going to say or what I'm going to do about something, and sometimes I just have no patience and I just get a little bit rough but most of the time I try to just, it's an ongoing thing you have to keep practising it every day, you can't just change that once and then it's done. (Family 1)

Parents spoke to the importance of remaining calm and patient, avoiding angry responses that could trigger and escalate their children's problematic behaviours, and worsen the situation.

However, parents noted that remaining calm and patient was not always possible as they were challenged in different ways. Thus, managing emotions was an evolving process as parents learned to make sense of, and work through, their own emotions and the emotions of their children.

Mother: You learn so much patience with these kids [laughs] because you just can't get mad, you just have to say "look, you need to listen carefully. This is what I said," and repeat it again without getting angry 'cause if you get angry then they get defensive and they get upset and, and I've found that you have to maintain calm, I mean, not to say I never lose it, 'cause I do sometimes. (Family 2)

Father: More patience is something I'm always working on, and that's a big one, just okay, I'm going to give you just a little more time, a little more space and try this a different way, another adaptation of talking to him in a different way, so not, for instance, just telling him to do something but trying to find a way to make it work for him. (Family 4)

Parents shared how they learned to control their emotional response to their children through coming to understand and accept the AS. In coming to accept that their children would always have AS and that they could not change the difficult behaviours, parents' developed a greater ability to remain calm and centered during challenging circumstances. One father shared how he and his wife manage their own emotions in relation to their daughter's verbal assaults and obstinate behaviours in the following quote:

Instead of getting all worked up about it, and being traumatized, both [Wife] and I kinda laughed about it, you know, what else are you gonna do? I mean, she's still got Asperger's, as much progress as she's made, it's all about her, and she can't understand our point of view so what do you do? You know, we get more chuckles from her behaviour now than we do trauma because we understand the little game she plays to try and work us, so it's not as upsetting because we know what's going on now. (Family 7)

While anger and frustration were common emotions that parents struggled to manage, they also mentioned anxiety and fear in relation to their children not being able to keep safe during emotionally intense situations, and being at risk of attempting or completing suicide.

Mother: I know that there are kids with Asperger's who've killed themselves because in that moment they can't think outside that moment and, with [Child with AS], he can get so upset about something like losing something or letting someone down that he can't let go of the feeling, and so that makes me paranoid, and worried. When he gets really upset about something now I almost don't want to let him just go away, I want to talk to him, talk him down off the ledge a little, when he's just like "Just let me walk away from you!" this feeling in me kicks up like I just need to make sure I feel like he's at a safe point to let him go. (Family 4)

Thus, in dealing with their children's challenging behaviours, parents experienced a complex array of emotional responses. The work of managing emotions was draining for parents as they were compelled to reflect on their own, and their children's, emotions "in the moment," and self-correct as needed to avoid escalating their children and worsening the situation. In the process of managing their own and their children's emotions, parents had to decide whether to intervene and teach their children how to be different or let go and accept their children's AS difference, which will be discussed next.

Balancing teaching and letting go.

Just as enhanced understanding and adjusting expectations enabled parents to better manage their emotional responses, it also facilitated their ability to effectively alter their behavioural responses to their children's difficulties. This occurred as parents made a distinction between what they could change and what was outside their sphere of influence as a result of the AS and the particular circumstances at the time. Parents began to balance their efforts to bring about change by teaching with accepting behaviours and letting go of the need to have their children be different.

Mother: I'm still frustrated sometimes with his attitude, and I was thinking about that this morning as we were driving to school because he had been grumpy with me this morning. And I'm thinking "He's got Asperger's, I gotta let it go." But then you've also got to try and find a fine line between letting a lot of the stuff go and teaching him how to react differently so a little bit more positively. So, it was just mostly understanding and letting a lot of things go. (Family 1)

This work of balancing teaching and letting go by deciding what was in their sphere of influence was challenging and unclear for many parents. Parents often second-guessed themselves, and wondered about the best approach for effectively managing their children's behaviours. One father explained it this way:

That's another one of those balance things where am I helping him to see that what he's saying is not appropriate or am I just basically shutting him down and I'm not gonna make any difference 'cause he's still going to want to talk about that anyway actually and he's not going to change, and I'm just being rude to him. (Family 4)

Parents had to carefully determine whether teaching their children to behave differently was critical at that particular moment in time or if it would make the situation worse. This entailed parents to develop critical judgment in reading their children accurately, and determining how far they could reasonably go with their teaching. At times, parents found themselves making sacrifices and withholding their inclination to teach, as described in the following:

Father: It's quite a sacrifice to me zipping your mouth up, and a lot of psychological emotional sacrifice goes into it because you think what [Child with AS] is doing is wrong but if you start attacking her behaviour too much then it felt like you weren't gonna accomplish anything, you were just gonna make the situation worse. (Family 7)

Parents assessed the context surrounding the behaviour, determining whether the behaviour was related to such things as a sudden change or anxiety-provoking event in the child's environment or whether the behaviour was related to the child testing the parental limits for acceptable behaviour. If it was the latter, parents often decided to challenge and teach their children how to behave differently, whereas, if it was the former, they decided to accept the behaviour and let go of the need to teach or 'push' their children to behave differently.

Mother: We'll challenge him but there are times of the year where we just don't push it. That first week back to school, that was like, sorry, Crocs [casual, foam clog shoe] is what he's got on his feet 'cause it's that or he's not gonna be able to sit through class. So, if running shoes are really important today I can make him wear running shoes but something else is gonna be sacrificed. (Family 3)

Parents not only balanced whether teaching would make a difference or not but also whether the teaching should come from themselves or from making mistakes. Thus, parents not only 'let go' because they believed they could not influence their children but they 'let go' because they believed that life could teach their children a lesson more effectively than they could.

Mother: Parenting too is about trying to protect him from not being successful and not being able to do well in a situation but at the same time still encouraging him to do his best in those situations. So there's a fine line there sometimes between "Do we let him try it?" (laughs) or "Do we just say no?" (laughs), right, because there's sometimes where we can look at a situation and know that it's probably not gonna turn out very good (laughs) but sometimes learning from the failure or the misattempt at it is more beneficial than me trying to explain it to him in another way, so it's a bit of a balance. (Family 3)

Mother: Well, you have to guide them but at the same time they do have to go on their own at some point, and make decisions, and make mistakes so that they can learn from them, and that's hard to do with any child but with an Asperger's child I suppose it's even more so. (Family 5)

Overall, the balancing of teaching and letting go was challenging for parents as they found themselves constantly reading their children, gauging the situation, and determining whether their teaching would be successful or if it would aggravate and escalate their children. There was a fine line between teaching the child how to be different and letting the child's behaviour go, accepting the difference and setting aside the need to intervene. Parents carefully gauged how far they could reasonably go with their children, which extends to balancing flexibility and structured routine, as discussed next.

Balancing structure and flexibility.

In raising their children with AS, parents were called upon to find the best approach to effectively manage the challenging behaviours, and this required problem solving and experimentation. In recognizing their children's resistance to change and insistence on structured routines, parents worked hard to establish structured, predictable routines for their children to

accommodate the AS. One family created a specific routine to ensure their child attended to personal hygiene needs (e.g., toileting, showering, shaving), and explained it this way:

Mother: He definitely needs a structure, there's certain things that we've done, like training him for the washroom, that was always a major problem, and he was coming home dirty from school every day...and that's very common with Asperger's, right, is the toilet training, so we struggled through that for so many years and we just couldn't come up with something, and then, between [Husband] and I, we got into a bit of a pattern to say "If nothing else we're gonna make him go to the washroom every night." So we got into a pattern of he could take his computer upstairs at 8:30 every night and he's got a little table, a little tray, and he puts his computer in there, and he plays on his computer, and he has to stay in there until he goes to the washroom and then he has his shower, and then Sunday nights he has to shave after the shower and clip his nails, and he has to come down and fill up all his pill jars for the week, and that pattern has been huge. I'd say within 2 to 3 months he never had another accident, they're very rare now. (Family 6)

Although parents established structured routines in advance to soothe their children's need for consistency and predictability, they were also faced with unpredictable moments where their children's needs and abilities called upon them to be flexible in the moment and adapt their routine "on the spot." Thus, parents were required to become supremely flexible, adjusting their adjustments to assuage their children and maintain family functioning, as noted in the following quote.

Mother: [Child with AS] may be convinced that Saturday morning is grocery shopping day but at the same time be absolutely convinced that he can't go grocery shopping. So as much as he needs the shopping to happen he can't go...so it becomes this balancing act of "Okay, well I'm gonna do shopping at 9 o'clock with [daughter] and then you don't have to go, and then the shopping can still get done." There's always this constant need for structure but at the same time that structure still needs to be bendable and mouldable to suit him on any given day because his needs change. (Family 3)

In response to their children with AS's varied and unpredictable needs and abilities, all family members were called upon to be flexible in their understanding and approach, adapting routines as needed to accommodate the AS. One family described how all family members have gained an understanding and acceptance of the child with AS, which has in turn enabled a greater ability for family members to develop enhanced flexibility.

Mother: When [Child with AS] is hyper-focused, my younger two kids will say “Aw, Mom, he’s stuck again,” because they recognize now that it’s really not [Child with AS’s] choice to not be able to move on from whatever it is that has him completely occupied...he can just fixate on and be stuck there for hours and hours, sometimes even days, and so when those things happen, plans may need to change, and our other children have learned incredible flexibility...so there’s this balance of needing the structure and needing the routines but at the same time there needing to be flexibility with other family members so we can make adjustments to accommodate [Child with AS]. (Family 3)

However, there were times where siblings did not feel it was fair for the child with AS to become the focus of everyday routines, and sometimes became jealous. As one mother explained:

That jealousy thing, it has taken a few years for [typical child] to come around and realize that things are different because [child with AS] is different. We have to do things differently. It’s not that we love him any more than you. It’s just the way it is, that he needs that time. (Family 2)

Although parents explained the AS to their typical children to encourage understanding and flexibility to accommodate the difference, they were also conscious of the unfairness of sibling sacrifice. As a result, there were times where parents decided to teach their children with AS how to be more flexible and allow siblings the opportunity to decide how the family spends time together.

In addition to balancing structure and flexibility, parents also balanced maintaining dependence and encouraging independence, which will be discussed next.

Balancing maintaining dependence and encouraging independence.

Parents identified the tension they experienced between maintaining dependence and encouraging independence for their children with AS. Parents recognized the importance of ‘breaking the dependency,’ and encouraging their children’s independence. One mother described this balancing act in the following way:

You have to kind of break the dependency, I mean, we can go away for a weekend, and leave [Child with AS] on his own, and he’s fine, and people go “I can’t believe you can do that!” and I said, “Both my children have always been very independent, I’ve tried to instil that in them because one day they’re gonna be on their own and you have to,” you

know, and with [Child with AS] it's even harder because he is so dependent on me that I have to work harder at breaking those ties while still keeping the support there but making him independent as well. (Family 2)

Parents were prompted to encourage independence because they worried that they would become constant caregivers if they did not teach their children the skills to function on their own. Further, parents worried about what would happen to their children if they became ill or passed away, and could no longer care for them.

Mother: What does [AS] mean for [Child with AS]? Will I still be taking care of him when I'm 65 years old? What if I get cancer? Or I can't take care of myself? If something happens to me who will take care of my child? Because the system won't, even once we knew there's a system there. What is there for him as an adult if something happens to me? I guess those things sit in the back of your mind, you worry about all that stuff. (Family 6)

As a result of worrying about their children's ability to function on their own without them, parents began teaching their children life skills such as managing finances, buying groceries, cooking food, and cleaning a house.

Mother: We're getting into the whole thing of trying to predict like how is he gonna do once he's out of school, what's gonna happen. We know he's smart enough but is he gonna remember to set his alarm to get up in the morning, is he gonna remember to get off the computer at night to get some sleep, because food is very low on his priority... So we're into a whole new set of things about what's gonna happen now, trying to prepare him, and I keep trying to think "What does he need to learn?" He needs to learn some cooking skills, he needs to learn some banking skills. All these things that you realize you only have so many years left that you have him there to teach him these things. (Family 2)

This introduction to independence through teaching key life skills was done in a gradual way. Parents implemented small steps towards building their children's confidence in completing these life skills, slowly moving to the background while gently nudging their children further ahead and encouraging them to lead the way.

Mother: [Child with AS]'s talking about going to business school, and they do four years of it at the college here, which would be great... and we're hoping that maybe the first year he could be at home and then maybe after a year or two, getting him to the point of

maybe he can board out at somebody's place in town so over the four years, we can make a gradual adjustment and see how he does with school and dealing with school and that, you know, where he's still close enough we can keep an eye on him. (Family 2)

Although parents had hope for their children to achieve independence, they were also prepared for the possibility of their children's dependence on them to help with activities of daily living such as grocery shopping, cooking, cleaning, and managing finances.

Mother: With ['Typical' Daughter], we have every intent to believe that she's gonna graduate from high school and go to college and live on her own and be successful at that, and hopefully get married and have a family of her own. That looks different for [Child with AS]. We hope that he can live independently in our basement, and hopefully will only require us to check up on him occasionally, it just looks different. (Family 3)

Although parents recognized the importance of encouraging independence, they were invited to hold on tightly to their children, keep their children close, and maintain dependence. Parents worried that others would recognize their children's vulnerability, and take advantage of them.

Mother: I think I'm always going to worry, I have worries because he isn't able to read social cues very easily, I've often wondered about when he tries to make friends whether or not those people are going to see a chance to take advantage of him. (Family 1)

Mother: She is very naïve, and I would be greatly concerned if she did get invited to a party, what would be the intentions of the people there, and thinking oh well, let's see what happens if we give her something to drink, so that would be a great concern. (Family 5)

Mother: There's a part of me that worries that if he did go to a party, he might be taken advantage of because he's so desperate to fit in, and we've talked about drugs and all that other stuff but it's like "Wouldn't it be funny to see [Child with AS] really drunk, or either have something in his drink and see what he does?" (Family 8)

As parents managed this balancing act and navigated the different tensions, they tried to remain hopeful that their children would eventually learn the skills required to function independently. In fact, some parents noted beginning signs of progress in their children, which reassured them that their children were capable of learning independence.

Father: It's what you don't know exactly, that's probably what causes more worry than anything else, but when you see that he's able to solve problems on his own, then you realize those worries are a little unfounded. (Family 1)

In addition to balancing dependence and independence of the child, parents also balanced parental roles and responsibilities, which will be discussed next.

Balancing parental roles and responsibilities.

Parents emphasized the importance of working together as a team to manage the roles and responsibilities of parenting their children with AS. In working together as a team, parents identified and capitalized on each other's strengths and abilities. Mothers commonly found their strength in reading and researching the AS and liaising with professionals.

Mother: We've always been on the same page, I would do the research, and I would, for the most part, get all the information and I did all the meetings with the psychologist for the diagnosis and the results and I'd hand [Husband] the paperwork, he'd read it, we'd know what needed to be done, and I would make the arrangements. (Family 2)

Mother: I've become the specialist just trying to figure it out on my own, and then talking to [Husband], and working as a team to implement it. [Husband]'s the implementer and the guy whose been home and really supportive, and I'm the one reading and saying let's try this and let's try this and let's not give up and when he crashes I keep going, so we've got some balance between us. (Family 6)

Fathers most often found their strength in supporting mothers in the following ways: 1) assertively advocating for their children in meetings with professionals; 2) discussing decisions regarding services and supports with mothers; and 3) providing feedback on when mothers need to take a break and care for themselves.

Although parents were able to manage the roles and responsibilities of the household through teamwork and capitalizing on each other's strengths, they experienced significant challenges in the areas of career, social functioning, maintaining fairness across their children, and managing finances.

For some parents, the AS significantly challenged their career paths. As a few of the children were in modified school programs, there were more days spent at home, resulting in a greater need for a parent to be present. Further, in recognizing the unpredictability of behaviours and vulnerability of their children with AS, the decision was made to have one parent remain at home to provide the necessary care and support required. As a result, some parents had to set their careers aside, or significantly adjust their careers, in order to stay at home and manage their children with AS.

Mother: We try to trade off but [Husband] is home for probably more than three quarters of the time but that has severely impacted his career path and they've made that clear in his job that that is really impacting him right now so we're trying to get a better balance but it's been a problem, and that means that one of us is always home no matter what. If we choose to go out, we quite often, we will not leave [Youngest child] alone with [Child with AS]. (Family 6)

A few mothers described how they spent increasing amounts of time attending to the needs of their children with AS (e.g., picking-up medication, driving child to various service and support agencies) that they struggled to balance their other parental duties such as cooking and cleaning. One mother explained it this way:

My day off really isn't a day off, like most Mom's days off, like I've managed to get out of the house, get him to tutoring, get him to his mental health appointment, get him to his horse, therapeutic horseback riding lesson, get him to his swimming lesson, and then get him home in time to pick up his [siblings] in time to get him to meet with the occupational therapist at our house at 4 o'clock. It's like that's his day, that's my day off, and I haven't made dinner, I haven't cooked, like I just drove all day. I'm sure there are lots of other Moms that would say "Well, that's all I do all day too." It's just different. (Family 3)

Several parents described the challenges posed by their children with AS to fairness within the household. As the child with AS became the central focus of everyday life, several parents acknowledged how difficult it was to balance fairness across all of their children. Parents found themselves torn between meeting the needs of their children with AS and meeting the

needs of their typically developing children. One mother described how she balances fairness this way:

We also have two typical children who have developed normally and have normal friendships, and normal social desires outside of our home, so sometimes those things become challenging because we need to try and meet the needs of all of our kids at the same time where one of them's not quite there yet (laughs)...so being able to explain to our other children that those sacrifices are just part of being in our house but at the same time giving opportunity for their choices to become a priority and for [Child with AS] to have to figure out what his plan is gonna be to deal with it. So trying to balance those two things so that we don't ever have one or more children that's saying "What about me?" (laughs), you know, so for us that can be pretty challenging. (Family 3)

A few parents struggled to balance their financial obligations across their children, determining how to allocate funds according to all of their children's needs. This became a difficult balance for parents as they had to make critical decisions that did not appear to be fair.

One mother described it this way:

We sometimes think the biggest decision we've made for [Typical Child] this year was whether or not she could do [sports event] and whether 200 dollars a month for that is too much money but then at the same time we're talking about how do we afford a tutor at 50 dollars an hour and riding lessons 'cause there's only so much funding money in that pocket. So what do you let go of? So, at the same time we don't want [Daughter] not to have the opportunity but if we give her the opportunity then that means [Child with AS] can't do something, and the thing that we're asking [Child with AS] not to do is something that [Daughter] has learned naturally, so it becomes hard because those decisions seem to be heavy. (Family 3)

Although parents worked hard to allocate their time and attention equally to all of their children, they revealed that they were not always successful.

Mother: Fair for us will never be [Typical Child] will get equal time, she won't. That's just a reality. It's a reality that we've had to accept [laughs] as parents, which is hard because you want that, I want to be able to give her as much time as I give [Child with AS] every day but I can't, I don't have that many hours in my day. (Family 3)

As a result, parents often found themselves "going the extra mile" in parenting, spending as much time and energy they could on their typical children and making space for their interests. However, there were times where parents had maximized their resources and could not

fulfill their goal of giving equal time and attention to their typical children, which left them feeling guilty.

Mother: I think I still don't give them as much as I'd like to but maybe every parent feels that way. I feel like I suffer from lack of sleep because I give so much to make sure that they get it, you know, I'm still sitting with [Typical child] at 11 o'clock at night because she's laying on my bed and she wants to talk, you know, it's just to do that. (Family 6)

Mother: It's not fair that [Typical child] sacrifices so much for [Child with AS] even though he has no clue, but she does, that's a reality. Is it fair? Absolutely not but it's her reality too. And so there's a point where you have to say "You know what? No, it's okay for her to have something. It's okay for her to take a weekend out of our time 'cause he takes countless hours every day," like it's okay for her to take 2 days for her [out of town event]. (Family 3)

In recognizing the high levels of stress involved in parenting their child with AS, parents spoke to creating their own respite, having a balance between spending time with their child and spending time with each other.

Mother: There is absolutely no way that anyone in this family can be off, ever, and that is a stress in and of itself. I don't think that we've actually ever put anything in place to cope for us. This year was the first time in the 20 years that we've been married that we actually went away for five days alone without the kids because we didn't think that we could ever leave him with anybody that would understand, and prior we didn't know why we couldn't leave him. (Family 6)

Overall, "regaining our balance" is a process in which parents were pointed in the right direction by their children's diagnosis of AS, and developed strategies for managing the complex and varying tensions of parenting their children with AS. As parents carefully gauged how to approach their children and manage the tensions present, they were witnessed by an audience of others, comprised of strangers, extended family, and professionals. At times, parents were tentative in their approaches for working with their children as they forged ahead into unknown territory. As parents gained expertise in reading and managing their children with AS, they gradually found a better balance for themselves as parents, their children with AS, and their family as a whole. In fact, some parents noted how some areas of parenting became easier as

they gained experience with handling their children's behaviours and were able to identify the triggers, deciding whether to avoid or plan for problematic situations. As parents gained expertise in parenting they also gained insight into what is helpful and what is not helpful in parenting a child with AS, and offered key advice for helping others (i.e., parents and health care professionals) find their balance, which will be discussed in the following section.

Helping Others Find Their Balance

This section will present parents' recommendations for helping other parents raising a child with AS, and the professionals who work with them.

Advice for Parents

Parents' recommendations for other parents raising a child with AS centered around four key areas: 1) Advocating for help; 2) Becoming informed; 3) Appreciating your child; and 4) Reaching out to others.

Advocating for help.

Parents recommended the importance of advocating for help upon first noticing the signs of a difference in their children. They suggested that other parents avoid self-doubt and blame, and trust their intuition.

Mother: If your heart says that you know something's wrong then do something about it, the earlier the better. I mean, if you know something's not right at pre-school but you don't know what it is, push them, advocate, and use the medical system. (Family 3)

Mother: If you know in your heart that's not right then do something about it, don't be afraid, don't blame yourself, 'cause we did, we looked for blame in every place we could find 'cause we just couldn't find a solution. (Family 6)

Parents advised other parents to challenge unhelpful help from professionals, seeking out second medical opinions and persevering in the face of adversity.

Mother: If you're not happy with the diagnosis you have, I would search and go somewhere else and find someone else, because the first doctor we saw it was Pervasive

Developmental Disorder-Not Otherwise Specified, and I said, “Okay, so now what do we do?” And he goes “Basically nothing, that’s it,” and it’s like “Okay,” and we were sent out of his office, and I wasn’t happy with that, and it took us just about 9 months to get in to see him too, so luckily because it had been just about a year, we were allowed to get referred to someone else. (Family 8)

Further, to aid parents in obtaining an early diagnosis of AS for their child, a key recommendation was made regarding the use of a video camera to capture the child’s differences and validate parental concerns to professionals.

Mother: If no-one’s believing you, set up a video camera and have it somewhere and get the child on tape doing something, I think that’s the best way, ‘cause we did not get [Child with AS], the doctor did not believe us until he actually behaved badly in her office one day, and then it sort of clicked for her, it’s like “oh,” and I was like “That’s what I’m telling you” but if they’re not doing it, how’s anyone gonna know? (Family 8)

Overall, parents recommended that other parents trust their inner knowing, and persevere in advocating for themselves and their child. Parents largely recommended that parents pursue help in the child’s early years because: 1) the funding is significantly more substantive than in the adolescent years; 2) the child can gain access to the early intensive services and supports to improve his/her level of functioning and promote successful outcomes into adulthood; and 3) the family can gain early access to resources to support them in understanding and managing their child with AS.

Becoming informed.

After receiving their children’s diagnosis of AS, many parents emphasized the importance of becoming informed about the AS. These parents gained knowledge through a wide array of resources, including autism-related books, conferences, and websites, which helped parents to learn more about their children, parent effectively in the context of AS, and gain social support. As a result, parents recommended that other parents become informed using similar resources. One mother offered the following advice:

That's probably my advice for people, read lots of books and go to conferences. It was a really good experience for me. We had to spend a lot of money, but I still look to see where other conferences are because I want to take [Child with AS], and I want to learn more. I want [Child with AS] to hear what I've heard, and to meet some of the parents and service providers that I met, and experience the atmosphere of happiness. (Family 4)

Two mothers specifically recommended Tony Attwood, an autism expert and clinical psychologist in Australia, who has written helpful books on Asperger's Syndrome. One mother found Attwood's books in addition to Dr. Ross Greene's "The Explosive Child" to be particularly helpful as they helped to explain her child's behaviours, and provided insight into his world.

Mother: I would recommend reading books. Tony Attwood is excellent, absolutely excellent. The Explosive Child, that was the first book I read, and I was in tears, through a lot of it, I mean a good chunk of it described him to a tee. (Family 4)

Further, the website "OASIS," or Online Asperger Syndrome Information and Support, was recommended as a helpful source of information on AS. One mother drew upon this resource in addition to books to help her learn more about her child's condition. In learning more about the AS, parents were able to understand their children's differences, gaining a greater acceptance for, and ability to manage, their children. As one mother succinctly stated, "I do what I have to do, I read, try to understand, and the more I understand the better it gets." Overall, the pursuit of knowledge was vitally essential for parents in helping them learn more about their children, the AS, and effective parenting strategies, which helped them in finding their balance.

Appreciating your child.

A few parents highlighted the importance of appreciating the child, and accepting the AS difference. They recommended cultivating an appreciation for the unique strengths, talents, and abilities of their children's difference.

Mother: Appreciate your child because they're wonderful, and a lot of people will say too having Asperger's is a gift. Some people would call it a disability, other people call it a

gift. They say some of the smartest people in society for hundreds of years likely had Asperger's. (Family 5)

Parents affirmed that, in spite of the challenges associated with AS, they would not trade their children or the AS.

Mother: I think that he's a wonderful, wonderful boy and he's got a wonderful personality and wonderful characteristics when he let's them out, and I wouldn't trade him for anything. (Family 1)

Mother: He's really gifted, and we have him for a reason, and [AS] is very hard to parent but it's still a wonderful thing, we wouldn't trade it. (Family 6)

These parents found a way to openly celebrate the AS. One family found that this open celebration of her son's AS helped to challenge the stigma surrounding the condition.

Mother: I'd say celebrate it like we do, to try and help combat that stigma, it's a part of who they are, don't try to be shameful about it because they feel that... the only way you get rid of [stigma] is to open up about it and for other people to see that this wacky, fun, smart little bugger has Asperger's Syndrome, and then they go "Oh, well that's not so strange then, is it?" (Family 4)

Overall, parents conveyed how they made sense and meaning of having a child with AS, reaching acceptance and appreciation of their child's unique qualities and traits. Parents emphasized the importance of appreciating their children, and not letting the AS define, or limit, their children's abilities. Through acknowledging their children's unique intellectual and personality traits, they were able to shift their perspective to the positive, which helped at times with managing the challenges and finding their balance in parenting.

Reaching out to others.

Lastly, a few families recommended the value of reaching out to, and receiving support from, others such as friends and work colleagues.

Father: Don't be afraid to tell people what you're going through because I mean, that's one thing that [Wife] and I have never hesitated to do is to let people know that we had a child that had problems and what was going on, and people that we could trust, we told

them what was going on, and we found a lot of support from our friends and associates that we could trust with the information. (Family 7)

Some parents found support groups to be particularly helpful as a safe place to go where they would not be judged by others but rather understood and affirmed in their parenting experiences.

Mother: At our support group we say that it's so nice to come where you don't have to defend your decisions, you know, people say "Why don't you just smack him?" or "Why don't you just do...?" and you have to go "Cause he doesn't understand," and you're always having to justify what you do or how you treat your kids. [That doesn't happen in the support group.] (Family 2)

Reaching out to others was an important recommendation for affirming parents' experiences of raising their children with AS, and connecting parents to a supportive group of individuals. This level of positive, affirming support from others validated parents' experiences as 'real' and helped them feel confident and less isolated as parents, which facilitated the process of regaining their balance.

Advice for Health Care Professionals

Parents' recommendations for health care professionals centered around three key areas:

1) Early identification and intervention; 2) Tailoring services and supports; and 3) Respite.

Early identification and intervention.

Parents emphasized that the earlier children with AS can be identified, tested, and diagnosed, the earlier they can receive services and supports to assist them in managing AS. Further, they noted that detecting AS early could limit the downstream costs and suffering associated with children with AS going undiagnosed and developing poor health outcomes. One mother described it this way:

If there's a child with a behavioural issue, particularly if they have Attention Deficit Disorder or other things that are early presenters of AS, it's not gonna hurt to do the testing, it's gonna cost society so much less to do a couple of extra psych analysis early

than it is to just let these people and these children struggle for years, and watch everything fall apart because nobody knows what's wrong. (Family 6)

As a result of the benefits of early identification and intervention, parents recommended that school and health care professionals receive autism training to learn how to recognize the symptoms early and facilitate a diagnosis.

Mother: The training to identify the problems with the child, the school system and the general practitioners, if they had more training and more skills in identifying this early, I think how many children have slipped through the system, and quite literally are living on the streets because their parents couldn't cope. (Family 6)

Parents recommended that school professionals receive education to challenge their misconceptions surrounding AS, learning that AS is not readily visible and may be masked by a seemingly 'normal' physical appearance and high level of verbal and intellectual ability. Parents recommended that early identification should take place in the school system where school professionals can administer screening tests (e.g., psychological assessments).

Mother: If it can be caught very quickly, and the one place where you will see things that children don't fit in socially is particularly those first couple years of school, and if they see things that aren't going right, I think the money should go more towards investing in the psychological reports at that time. (Family 6)

Mother: If this study leads to anything, it should lead people to say "Hey, we need to do something." That's probably the number one thing. That structure really needs to be there to identify these kids whether it's Asperger's or whatever. If there is something wrong at school that doesn't seem right, it's not just parenting skills, it's not just that child is bad. In my mind there's no such thing as a bad child. They need to look further, and they need to have that funding available to check out what's wrong with those kids. (Family 6)

Mother: I don't know if it's in place but in my mind it would make sense for some of these kids in trouble to have some kind of screening tests...like somewhere in the primary school system. (Family 7)

This recommendation for autism training was not limited to professionals but extended to community members as parents believed the more trained, educated, and aware others in the

community (i.e., family, friends, strangers) are about AS, the more understanding and accepting they will be of their children.

Father: Another thing I would recommend is train the world, everybody needs to be aware of individuals' disabilities, different people treat it different ways, some teachers at school treat a kid like [Child with AS] as just a behavioural problem but he's fully capable, he probably understands more of the topics than we do. (Family 6)

Overall, parents emphasized the importance of early identification and intervention in the school context where the social and behavioural problems became most apparent. Parents highlighted the critical need for school professionals to explore all possible explanations for the child's differences, avoiding hasty conclusions of parental and child blame. In order for the testing to be done in the schools, parents recommended that professionals be trained in the area of AS and have the funding available for psychological testing. Parents believed that if this early testing had been offered, their lives would have been significantly improved as their child and family would have received the understanding and support they needed to help them find their balance.

Tailoring services and supports.

Parents recommended the importance of professionals tailoring services and supports according to the child's needs, interests, and abilities.

Mother: I think sometimes each of the kids with AS need a group thing but they also need an individualized thing too 'cause they all have such different components, so someone that can work with them one on one on different stuff and not get sidelined by the other stuff...it's tough to know what each [child with AS] wants or needs but maybe the kids themselves know, like to say "If someone was going to come work with you or help you with certain things, what kinds of things would you want them to teach you, or help you with, or talk to you about?" (Family 8)

Parents highlighted socialization groups as a key recommendation. Parents advised that these socialization groups need to take place in real-world settings such as at the movies or a restaurant where their child could learn practical and useful skills for managing life.

Mother: I would recommend something like let's do a cooking class for teens, and we're going to tell these kids we're gonna do this cooking class and they're gonna learn to cook but you have all these boys there that are like him who lack on the social end... and they're learning something at their level that they would find interesting or challenging, and don't even realize that they're going to a socialization class... we want them to be typical but we're teaching them as special needs, if you want them to be typical then teach them to be like typical kids, don't teach them as special needs. (Family 2)

Parents also recommended that professionals begin teaching life skills in the teen years to build the knowledge and skills needed for children with AS to function independently and manage adulthood with success.

Mother: I would like to see more life skills, like for after high school, maybe living on your own, going to university, what it's going to be like, you know, something that's age appropriate because he's getting to that age. (Family 8)

Parents also recommended health care professionals provide clear and coordinated care, especially after the diagnosis of AS is given and parents struggle to orient themselves to the appropriate services and supports for their children. Some parents struggled to understand the complex, medical language used in the handouts and information packages on autism-related services and supports, and they lacked the time to conduct their own research to seek out the appropriate services and supports for their children. As a result, parents recommended that professionals facilitate this process of seeking out helpful resources through the use of a clearly written and comprehensible guide-book or "road map," outlining the appropriate services and supports based on their children's age and specific condition on the autism spectrum.

Further, it was also recommended that professionals follow-up with the family after the diagnosis to ensure they are accessing appropriate and helpful services and supports for their child. For some families, there was no follow-up from professionals after the diagnosis, and, as a result, they highlighted the importance of being persistent in contacting professionals and seeking helpful services and supports for their child.

Mother: I think if a parent wasn't as persistent as us they would probably get a little bit frustrated and overwhelmed by trying to figure it all out. So that initial meeting with [community resource], where she signed everything off, she said "Oh, here's the autistic funding paperwork. If you go to a provider this is what you have to fill in to get the money, and here's the booklet." We've had no meeting. I think if there was a follow-up once a month for the first little while to say "Okay, based on the age of your child, let's write a plan for the next year of some of the resources you should access." (Family 6)

Overall, parents advised health care professionals to individualize and tailor their approach to the child and family, attuning themselves to the specific needs, abilities, and interests of the child and opening lines of communication with parents to ensure the provision and maintenance of best care.

Respite.

A few families recommended respite to allow a break from the stress of being constant caregivers. One family noted how respite would have allowed them to spend quality time with their 'typical' children, providing a well-needed break to experience 'normal' family life.

Mother: So much of it comes back to the one core thing, I think if we had the support and the structure and all those things from a very young age it would've all been there, like [Child with AS] could've went to camp for the summer, or for a few days some respite, where we could've taken each one of the children and went camping or just went away and had that one on one that you need with your children...just so that they could breathe, so that they know what it feels like to be normal. I think that would've been huge. (Family 6)

However, as parents noted, respite is typically reserved for families experiencing severe forms of autism where the child needs daily medical care. As a result, parents were denied this resource.

Mother: When you do look into the funding and try to meddle through those thousands of papers, there is no respite...there's not even respite for under 6, unless it's pretty severe autism where they need an actual person like a nurse to come and feed them and change them and stuff. So, there's no respite for someone who is physically able, and [Child with AS] is definitely physically able, he feeds himself, he eats, that's been a non-issue. So, I don't think they recognize respite from emotional stress. (Family 6)

As respite was denied to the families because their children had an average to above average IQ and did not have severe physical health needs, they decided to create their own respite. Parents created their own respite in different ways, including sending their child with AS to a school for children with exceptional abilities, making time to pursue their own hobbies and interests, and scheduling annual vacations where they could go away as a couple or with their ‘typical’ children. These parents were able to leave their children with AS in the care of another person (e.g., family member or friend), thus allowing parents to manage the financial implications of pursuing their own respite.

Through creating their own respite, these parents were able to achieve some semblance of balance in their lives, returning from their breaks with renewed energy to effectively parent their children with AS and manage family life. As a result, they recommended that health care professionals recognize the myriad challenges of parenting a child with AS, and provide the respite that parents and families need.

Summary

Parenting a child with AS involved a delicate and precarious balancing act. Initially, parents started out in-balance as they were comfortable with handling their children’s differences, and believed they had a ‘unique’ but ‘normal’ child. However, as the differences grew and developed into problems, parents became seriously challenged in their ability to parent and experienced a lack of parenting success (i.e., they were unable to help their children be ‘normal’). In seeking answers, parents looked to themselves and each other for the source of the problem, and feelings of blame, guilt, and helplessness arose. When parents asked professionals for help, most did not receive the help they desired and needed. In not knowing what to do to help their children, parents began to flounder and became worn down. For some parents,

continually receiving unhelpful answers almost finished their ability to parent as they reached crisis points, prompting them to consider leaving their family or removing the child.

This process of losing their balance was frustrating and unsettling for parents as they felt defeated in not having any reasonable answer to explain their children's problems and help them parent effectively. Through this difficult time, parents continued to persevere with a desperate hope and devoted determination that they would eventually find the answers they needed. When parents finally obtained the diagnosis of AS for their children, they could see "light at the end of the tunnel" as the diagnosis pointed them in the right direction towards restoring their balance. With the diagnosis, parents could learn about and understand their children's condition, and access a wide range of services and supports.

As parents learned how to effectively manage their children and navigate the services and supports with success, they developed expertise in parenting a child with AS. Parents were able to translate this expertise into key recommendations for other parents raising children with AS, and the professionals who work with them.

Overall, parenting a child with AS is a complex and evolving process in which parents struggle to find the right balance for themselves, their child with AS, and their family as a whole. This chapter presented the key findings from this study, which will be discussed in the following chapter along with implications for practice, education, and research.

CHAPTER FIVE: DISCUSSION, IMPLICATIONS, AND CONCLUSIONS

In this chapter I will situate my study within the current autism-related literature, and discuss how the findings confirm and advance current knowledge about the experience of parenting a child with AS. A synopsis of the findings will be presented, and implications of the study findings for practice, education, and future research will be detailed.

Synopsis of Findings

The purpose of this study was to describe and explain the nature of parenting a child with AS. A total of eight families were recruited with 8 mothers and 5 fathers participating in the interview process. Analysis of the interview data resulted in the identification of the core construct of parenting as a ‘balancing act.’ This balancing act elucidated the nature of parenting a child with AS, shedding light on the dynamic and complex qualities of the parenting experience. The balancing act was comprised of three key themes: ‘losing our footing,’ ‘regaining our balance,’ and ‘helping others find their balance.’

In the process termed ‘losing our footing,’ parents described their experiences leading up to the diagnosis of AS, which included noticing their children’s differences, running into problems, searching for answers, encountering parental blame, receiving unhelpful answers from school and health professionals, persevering through the problems, and running into crisis points. The experience of knowing something was ‘different’ about their children but not knowing exactly what the difference was or how to help the child respond to significant problems unsettled and unbalanced parents. Although one family experienced a direct and smooth path to the diagnosis of AS for their child, for most families the path to diagnosis was difficult and uneven. Many families found they had to persevere through the problems, sometimes “going it alone” to access alternative schooling options and health care services outside the public sector.

Two families experienced crisis points where the extreme and constant levels of stress in the household and the exhaustion of all resources for coping and seeking help reached a breaking point, and family integrity was threatened.

When parents finally received the diagnosis of AS for their children, they began the process of ‘regaining our balance.’ The AS diagnosis played a pivotal role in parents’ lives, helping them make sense of their children’s differences, affirm their experiences as real, and gain access to helpful services and supports. Although the diagnosis was largely experienced as “good news” it did not immediately restore balance for parents. As parents researched the AS, gained AS-specific parenting skills, and experimented with new strategies for managing their children’s differences, their confidence in parenting was gradually restored, which enabled them to regain balance.

The balancing act of parenting a child with AS was iterative and dynamic as parents moved between states of imbalance and balance. The constantly shifting and unpredictable nature of their children’s needs and abilities challenged parents’ ability to maintain balance. Parents encountered times where all efforts to manage their children’s behaviour were unsuccessful, and other times where their strategies were met with successful responses and outcomes. Thus, the work of balancing was precarious, and involved carefully reading the child and developing a repertoire of strategies to respond to challenging and changing situations.

As parents sought balance for themselves and their children, they were observed by an audience of others (i.e., professionals, extended family, strangers), and described instances of either direct or perceived parental blame. Parents noted how their children’s AS was often invisible to others. Thus, in moments when their children misbehaved, parents felt compelled to defend their parenting decisions and educate others about their children’s condition. Parents

educated others through revealing the AS and interpreting the differences to encourage better understanding of AS, acceptance of their children, and an adjustment of expectations. In this way, parenting was not solely an activity between parent and child but also included advocacy and education of others.

As parents gained expertise in balancing for themselves and their children, they were able to offer insight into ‘helping others find their balance.’ Parents offered key recommendations for parents and professionals interested in how balance can be nurtured, restored, and maintained in the context of parenting a child with AS.

Confirming and Extending What is Known

This study largely confirms what is known about parenting a child with a diagnosis on the autism spectrum, with the addition of findings that extend current knowledge and understanding. The findings that are consistent with previous studies and corroborate current literature will be presented first, highlighting the areas of blame and stigma, strength and resiliency, and identifying positive experiences. This will be followed by a discussion of how the findings extend what is known, detailing the areas of the parenting process that include identifying with their child, constructing their own ‘normal,’ persistent experiences of unhelpful help, the cost to family integrity, and children’s aggressive and self-harming behaviour.

Blame and Stigma

An important finding was continued experiences of parental blame, which has long been noted in the literature on parenting and autism, beginning in the mid to late 1950s and extending to the mid-1960s when psychoanalytic theory explained autism as the result of pathologic parenting (DeMyer, 1979; Schopler & Mesibov, 1984). The culture of parental blame largely focused on mothers’ parenting deficiencies as the primary etiologic factor in autism. With a

scholarly review critiquing psychoanalytic theory (Rimland, 1964) and advances in understanding the genetic (Folstein & Rutter, 1977) and neurobiological underpinnings of autism (Gillberg, 1988; Gillberg, Steffenburg, & Jakobsson, 1987; Steffenburg, 1991), blaming mothers has diminished. However, as this study confirms, in spite of advances in understanding the etiology and impact of autism, the psychological legacy of blaming mothers for their children's autism has lingered (Kuhn & Carter, 2006).

The findings from my study not only confirm the blame experienced by mothers but also highlight experiences of self-blame experienced by fathers. This finding confirms how blame undermines both mothers' *and* fathers' confidence in their own abilities and knowledge, and interferes with their ability to both parent and cope in the context of unremitting difficulties (Kuhn & Carter, 2006). This is an important finding that supports parental blame as a phenomenon that is not experienced by mothers alone (Neely-Barnes, Hall, Roberts, & Graff, 2011). Thus, there is a vital need for health care professionals and teachers to address mothers' and fathers' experiences of blame, and develop approaches and strategies that depart from the age-old myth and unhelpful explanation that parenting is the problem.

The experience of blame contributed to the stigma felt by mothers and isolated them from extended family and the larger community. The stigma left mothers feeling abandoned and alone with their problems. Mothers noted how visits with family relatives, meetings with professionals, and public outings could become problematic when they encountered normative expectations for their children's behaviour that did not account for AS. This finding confirms recent research on mothers' perceptions of stigma that found mothers frequently perceive stigma in school and community environments where others readily judged their children's disruptive behaviours and blamed parenting ability (Gill & Liamputtong, 2011). This finding also confirms past research

that mothers perceive more stigma than fathers and experience their parental competence called into question by others who view mothers as responsible for their children's behaviours (Gray, 2002). Overall, this study confirms that stigma is still encountered by mothers of children with AS, and continues to be a relevant issue for both mothers and fathers.

Strength and Resiliency

Throughout the challenging experiences of raising their children with AS parents drew upon personal and relational resources to adjust to and cope with the demands of parenting. Parents showed remarkable strength and resiliency in their ability to persevere in the face of often longstanding adversity, striving to find the answers they needed to help themselves, their children with AS, and family regain balance. It is important to note that all eight families in this study remained intact in spite of the myriad challenges they experienced in obtaining a diagnosis, managing the tensions of raising a child with AS, and losing then finding and maintaining balance in parenting. These dual-parent families found ways to support each other to maintain their family cohesion and integrity in times of extreme stress. This is a finding that is consistent with previous research on family resiliency and autism (Bayat, 2007), and lends further support to the notion that having a child on the autism spectrum does not automatically predict a high risk of separation and divorce among dual-parent families (Freedman, Kalb, Zablotzky, & Stuart, 2011).

Identifying Positive Experiences

In addition to their strength and resiliency in the face of adversity, parents also described the positive experiences associated with raising a child with AS. In fact, some families spontaneously introduced this topic, emphasizing and appreciating the positive traits of their children with AS. They remarked on their own personal growth and development associated with

parenting a child with AS, including increased acceptance and tolerance of difference. This finding mirrors previous research on the positive impact of raising a child with an intellectual disability (Stainton & Besser, 1998), including AS (Little & Clark, 2006), and how finding positive aspects in the parenting experience can be a constructive, meaning-making process integral to the parental work of adapting to and coping with raising a child with AS (Pakenham, Sofronoff, & Samios, 2004). It is important to note that the parents in this study had known their children's diagnosis of AS for at least 2 years. As a result, they had time to adjust to and make meaning of the diagnosis, which may have played a role in their ability to readily identify the positive aspects in their parenting experience. It is significant that parents were able to develop and utilize this positive lens as it sheds light on an effective coping strategy that may help other parents, and can be acknowledged and encouraged by professionals.

It is important to highlight that parents identified the positive aspects of their experience in conjunction with the challenges and difficulties. This confirms previous findings that parenting a child on the autism spectrum can include moments of joy and sorrow (Little & Clark, 2006). Further, it challenges the perspective that parents who share the positive aspects of their experience are overly optimistic, denying reality, and that they are not acknowledging the true nature of the condition (Scorgie & Sobsey, 2000). Rather, parenting a child with a developmental disability is often 'paradoxical' in nature (Larson, 1998), and is characterized by parents' ability to dwell within the space between joy and sorrow, acknowledging both the positive qualities of their children and the challenges of managing the condition (Kearney & Griffin, 2001)

Parenting as A Process

This study sheds light on the influence of the experiences associated with having a child with AS on parents' ability to parent effectively. Thus far, research on parenting a child with AS has addressed elements of parents' experiences such as diagnosis, treatment, and service provision (Chell, 2006), challenges and making meaning (Lasser & Corley, 2008), and the joys and pressing concerns (Little & Clark, 2006). These studies have focused on specific aspects of the parenting experience but have not focused on how parenting ability is specifically impacted at different stages from pre- to post-diagnosis of AS. The findings from this study capture the process of parenting a child with AS over time.

Identifying with their Child

This study found that mothers and fathers identified with their child, especially in the early years before the diagnosis of AS was received. The children's early differences invited parents to reflect on their own childhood differences. This helped them make sense of their children's behaviour and allayed their concerns. For example, parents in this study compared their children's behaviour to their own childhood shyness or social awkwardness. While identification with the child supported acceptance, it also supported delay in recognizing the behaviour as problematic. This finding suggests that identification with the child is more complex than previously understood. For example, Gray (1994) found that parents of children with autism identify with their children's differences as a form of coping, which may facilitate acceptance. However, the evidence indicates that there may also be a negative implication for this strategy in terms of delayed symptom recognition.

This finding not only sheds light on a possible factor associated with delayed diagnosis but also lends support to the familial clustering of AS and supports the theory of a "broader" or

“extended” AS phenotype” expressed within the family (Baron-Cohen & Hammer, 1997). This broader or extended AS phenotype represents the presence of mild, subclinical AS-related traits, most commonly social and communicative impairments, in undiagnosed family members of individuals with AS (Gerdtts & Bernier, 2011). The phenotypic expression of AS-like traits in family members of children with AS supports the genetic liability for AS-related traits in families (Piven, Palmer, Jacobi, Childress, & Arndt, 1997). Although there is credible evidence supporting a significant genetic component to the etiology of AS, understanding the broader phenotype in families of children with AS may prove helpful in elucidating how phenotype profiles may be inherited within families.

Constructing Their Own ‘Normal’

The findings illuminate parents’ struggles with constructing ‘normal’ for themselves and their children. Lasser & Corley (2008) conceptualized constructing normalcy as the parental process of meaning-making and creating adaptive outcomes for their children. They found parents made meaning of their experiences through developing an understanding of ‘normal’ for themselves and their children, and worked hard to create successful outcomes for their children. These authors focused on how parents understand ‘normal’ according to external, societal standards of ‘normal.’ This stands in contrast to the findings of the current study, which demonstrate how parents respond to a persistent lack of success in managing their children’s condition by constructing their own standard of ‘normal,’ and adjusting their expectations to more realistically align with their children’s needs and abilities. Parents also worked to influence others’ expectations of their children through explanation and education. Overall, findings from this study suggest that there is more to ‘constructing normalcy’ than is presently documented in

the AS literature, and that some families may construct ‘new’ standards of ‘normal’ to help them effectively manage and find balance in raising their child with AS.

Persistent Experiences of Unhelpful Help

Although the parents in this study had high levels of education and income, and demonstrated strong advocacy skills for themselves and their child, all but one struggled to obtain the diagnosis of AS for their child. Parents first noticed their children’s differences in the preschool years, around age 2 to 3, pursued help in the early elementary years, around age 6 to 9, and did not receive a confirmed diagnosis of AS until their children were, on average, 10.75 years old ($SD \pm 2.87$). This is consistent with previous research revealing parents of children with AS waited 5.5 years on average before receiving a confirmed diagnosis and did not receive a confirmed diagnosis until their children were, on average, 11 years old (Howlin & Asgharian, 1999). Although the autism literature does not specify what constitutes a ‘delayed’ diagnosis, there are consistent reports of a ‘significant’ lapse in time between the age at first parental concern and the age at first autism spectrum diagnosis (Wiggins, Baio, & Rice, 2006), with parents of children with AS waiting considerably longer than parents of children with classic autism (Howlin & Asgharian, 1999).

The families who struggled to obtain a diagnosis for their children emphasized their frustration and dissatisfaction with the diagnostic process and the inadequacy of the help they received. Further, two of the families experienced profound crises before they obtained their children’s diagnoses of AS. These families became acutely concerned for their children’s mental health and safety, and had to rely upon emergency mental health and hospital services to help them. These findings challenge previous research that suggests higher levels of parental education and income are associated with earlier diagnosis in childhood and greater satisfaction

with the diagnostic process (Goin-Kochel, Mackintosh, & Myers, 2006). The participating parents had significant resources available to them and still struggled with systems that were unhelpful and at times obstructive. Clearly awareness and recognition of AS among health and education professionals remains an issue.

Cost to Family Integrity

This study revealed the extreme difficulties that can be associated with parenting a child with AS and that can threaten family integrity. Fathers expressed more thoughts of leaving the family than mothers when experiencing extreme levels of stress. This finding supports the presence of gender differences in parenting a child with AS and suggests that gender-specific interventions may be helpful and necessary for parents. Overall, it was not a single stressor that threatened family integrity; rather, it was an effect of cumulative stressors over time. These stressors included parents' difficulty making time for the marital relationship and typically developing children, financial costs of pursuing help, tenuous and conflicted relationships with professionals, career sacrifices, experiences of parental blame, social isolation from extended family, friends, and the community, and the daily demands of often unsuccessfully managing the AS. A deeper understanding is required of how these stressors interact to challenge the marital relationship in dual-parent families, and the effective strategies and interventions for supporting the integrity and well-being of dual-parent families.

This finding raises the question of risks for single parents who do not have the supportive resource of another parent to help them cope with and manage parenting a child with AS. There is a lack of evidence examining the experiences of single mothers and fathers raising children with AS, and the effect of family type on the parenting experience specific to AS. Recent preliminary evidence suggests single mothers of children with AS are at particular risk of not

receiving the education and support they need from their communities and increased perceptions of stigma (Gill & Liamputtong, 2011). Thus, understanding single mothers' and fathers' experiences raising a child with AS is a relevant issue for practice that requires further attention.

Aggressive and Self-Harm Behaviour

Two families experienced behaviours from their children that are neither well cited nor well understood in the literature, which included aggression of one male child and the self-harm, 'cutting' behaviours of one female child. Although there is limited research on comorbid psychiatric conditions among children with AS, the available literature supports a strong link between AS and mood and anxiety conditions with depression being the most common associated condition in the teenage and adult years (Ghazziudin, Weidmer-Mikhail, & Ghazziudin, 1998). The presence of aggressive behaviours has largely been noted in relation to children with autism with little known about aggression in AS (Gray, 1992). However, recent research is beginning to show that aggression and disruptive behaviours can occur as psychiatric comorbidities in children with AS (Mukaddes & Fateh, 2010).

The self-harm behaviour points to a possible underlying depression. Self-harm has been cited as one of the most common symptoms of depression in children on the autism spectrum (Lainhart & Folstein, 1994). Anecdotal evidence grounded in clinical practice observation suggests that self-harm behaviours (e.g., cutting, hitting, pinching, or head banging) in females may serve the purpose of regulating challenging emotions, particularly when they lack well-developed coping skills (Nichols, Moravcik, & Tetenbaum, 2009). However, within this study, making meaning of this singular observation is not possible.

Implications for Practice

The findings of this study are helpful for professionals as they raise awareness and provide a more complete understanding of parenting a child with AS than is currently available. In particular, the inclusion of fathers' perspectives, and the inclusion of parents of female children with AS, is a major contribution. The findings emphasize that parenting a child with AS continues to be poorly understood, and, as the prevalence of AS continues to rise, more families will be in need of professionals in all settings and at all practice levels (e.g., nurses, physicians, school teachers) who understand their experiences and support them through the challenges (Inglese, 2009).

Clearly, parents are in need of more support than they are presently receiving from health care and school professionals. The findings suggest that parents are largely dissatisfied with initial responses and approaches from professionals, and serve as a reminder for professionals to take the time to listen to parents' concerns, affirm their struggles as real, and engage in comprehensive assessment before drawing conclusions about the child and family. The findings suggest that professionals can help parents by recognizing them as the experts on their children. As Gombosi (1998) aptly stated, "I don't think we can speak about what parents need from professionals until we recognize that parents are the most important resource a child has" (p.251). Thus, acknowledging and accessing parents' expertise regarding their children is a key strategy for not only establishing and strengthening the therapeutic alliance but for accessing important information to facilitate accurate diagnosis and guide appropriate treatment.

As parents noted some professional reticence to diagnose AS and affix a 'label' to their child, it is important for professionals to remember that an accurate diagnosis of AS can help families begin the process of finding their balance. In fact, delayed diagnosis was damaging to

the parents, their ability to parent, the child with AS, and typically developing siblings.

Professionals need to be aware that, with long lapses in time from first parental concern to the AS diagnosis, parents may have explained their children's differences through the lens of poor parenting, and experienced considerable self-blame and guilt. Further, this self-blame may be compounded by blame encountered from others (e.g., school and health professionals, extended family, and strangers). Thus, professionals will not only help parents by guiding and supporting them towards an accurate diagnosis of AS for their children but through working with parents to dispel some of the constraining beliefs they may have around being responsible for their children's problems, providing them with information on AS to help educate others, and supporting them towards feelings of competency in the parenting role.

In this study, two fathers considered leaving the family in response to the cumulative stress of having children with unexplained differences and lack of helpful answers from professionals. Further, one father experienced depression, and noted how the need for one parent to always be at home to care for his son significantly restricted his social life and career goals. This finding suggests that fathers may require services and supports specific to their needs, and that professionals need to include fathers in the provision of care to better understand their experiences and meet their needs.

Implications for Education

It is vitally essential for school and health professionals to be offered the education needed to recognize the often subtle presenting signs and symptoms of AS to aid in the early diagnosis of the condition. The findings reveal that identification of children with AS is being missed in the early years, resulting in children and families going for years with unexplained differences and unresolved problems. Delayed diagnosis is a serious problem and needs to be

properly addressed, especially considering the numerous benefits of an early diagnosis of AS such as improved outcomes, earlier access to funding and helpful services and supports, and reduced lifetime costs of assisting the person on the autism spectrum and their families.

Evidence-based research has revealed the lifetime costs of assisting a person with autism can be cut by 50% if an early diagnosis is provided along with effective treatments and adequate family supports (Autism Society Canada, 2004). As a result, it is in the financial interests of governments and taxpayers to fund the education of professionals to aid in the early identification and treatment of children on the autism spectrum, including AS.

In recommending that professionals be educated about the early signs and symptoms of AS, the question remains: “What do we look for in the child’s early years that may signal AS and support a referral for an autism assessment?” The findings from this study suggest that parents first notice the symptoms in the early preschool years, around the age of 2 or 3 years old. This is consistent with findings that show the first signs of AS begin to show at a mean age of 26 months (Noterdaeme & Hutzelmeyer-Nickels, 2010), and Autism Spectrum Conditions can be reliably diagnosed as early as 2 years of age (Charman & Baird, 2002). Further, this study identifies some early differences parents notice, including their children’s unusually quiet nature, preference to be alone or play alongside (but not with) other children, difficulty fitting in with peers and making friends, and exceptional islets of ability such as advanced memory skills, extensive vocabularies, and the strong, silent pursuit of interests exceeding age level. It is important for professionals to receive education on the deceptively subtle and seemingly invisible nature of the condition in the early years, and how differences can be masked by exceptional verbal and intellectual abilities. In addition, professionals need to understand that parents may express a hint of concern but may have developed their own explanations for the

differences or received other parents' recommendations such as "Just wait, he/she will grow out of it." Thus, parents may not be convinced at this point of the need to pursue help from professionals. Clearly, the parents in this study were more than ready for the diagnosis when it finally came. However, this may not be the case earlier in the experience. Thus, a key recommendation is getting professionals and parents 'in synch' in understanding the early and often subtle signs of AS, and the value and importance of receiving an early diagnosis. Overall, professionals play a key role in facilitating early diagnosis, and thus education needs to be provided to sensitize them to variances in early childhood behaviour and development that warrant referral.

Implications for Research

Autism Spectrum Conditions are more prevalent than other pediatric disorders such as spina bifida, cancer or Down syndrome (Filipek, Accardo, Baranek, et al., 1999). However, in spite of this increased prevalence, autism research funding has not kept pace when compared to funding associated with other medical conditions (Autism Society Canada, 2004). As the prevalence of AS rises more families will be in need of continued services and support across their children's lifespans. Thus, there is a vital need for more research funding to address parental and family experiences in the context of AS.

As the limited research on parenting a child with AS has privileged mothers' perspectives, there is a strong need for research that provides insight into the perspectives and experiences of both mothers *and* fathers. The findings of the current study as well as the work of Gray (2003) suggest that there may be gender differences in parenting that would benefit from further exploration. This study found mothers and fathers experienced blame, which undermined their confidence in their ability to parent and contributed to the process of 'losing our balance.'

This finding is just beginning to receive support in the literature (Neely-Barnes, Hall, Roberts, & Graff, 2011). Thus, further investigation is required to not only shed light on the gender differences in parents' experiences of blame but the gendered nature of parenting in general, and the identification of gender-sensitive and gender-specific interventions that acknowledge and address the different needs and experiences of mothers and fathers.

The diagnosis of AS is more frequently given to males than females, and thus the majority of studies on AS have recruited parents of male children with AS. This is an area that should not be ignored as parents of female children with AS have long been under-represented in research studies. Female children have been described as “research orphans” by Ami Klin, psychology and psychiatry professional at Yale’s autism program, because researchers who found it difficult to recruit enough boys in their studies have found it nearly impossible to recruit a comparative number of females, leading them to cull the females from their studies (Bazelon, 2007). There continues to be gaps in understanding parents’ experiences raising female children with AS, and how the gender of the child influences the parenting experience. This study included female children with AS, and the findings suggest that some parenting issues may be different for male and female children with AS. Further research is needed that focuses on and encourages the participation of parents of female children with AS, and explores gender differences in AS symptomatology and the presence of psychiatric comorbidity that influence parenting.

This study revealed how the challenges of parenting a child with AS can threaten family integrity, and the ability of parents to effectively support each other in times of unrelenting stress and crisis. The parents in this study described having to ‘go it alone’ and felt isolated by a system that expected them to take primary lead and do all the work themselves (e.g., finding help for their child, negotiating professional systems of care, maintaining marital and family integrity).

Thus, research needs to focus on interventions to support and strengthen the parental dyad and assist and guide parents in finding the help they need to manage parenting a child with AS across the lifespan.

This study shed light on parental identification with the child, and elucidated how, in some cases, mothers and fathers may have qualitatively similar behavioural traits as their children. This finding extends Gray's (1994) finding that parents identify with their children's differences as a form of coping by suggesting a possible factor contributing to delayed diagnosis. Further, this finding supports the genetic underpinnings of AS, and suggests the need for further research examining the patterns and boundaries of phenotypic traits in parents, siblings, and extended family members of individuals with AS. Thus, the following questions are raised for further study: "How does parental identification with the child influence the diagnostic process?" and "What are the features and extent of the broad phenotype in families of children with AS?"

The participants in this study were well educated, financially secure, and professional parents who resided in central B.C. and were able to maintain their marital relationship in spite of very serious cumulative stressors. The parents had access to resources and were able to respond to the call for participants for the study. Thus, the parents represented a unique sub-set of the population of parents raising children with AS. This prompts the following questions: How do families who are resourceful but do not have the same access to resources (e.g., education, income, the support of a partner) find their balance while parenting a child with AS? What about families who do not fit this profile (e.g., single parent, same-sex, grandparent-headed, and adoptive)? What role does geographic location play in parents' access to resources and overall experiences of raising a child with AS? Overall, further research in this exploratory field of parenting a child with AS requires larger studies with more heterogeneous samples,

including diverse family backgrounds (e.g., education, economic, cultural), family types (e.g., single-parent, same-sex, skip generation families), and geographic locations.

Conclusion

In this study, I explored the nature of parents' experiences raising a child with AS. Findings from this study elucidated the complex and dynamic nature of parenting as a balancing act, which served as the common thread throughout the parents' narratives. Parenting a child with AS was challenging work. Parents fought to maintain their balance and parent effectively in the face of persistent pressures, including unhelpful responses from professionals, lack of parenting success, and increasing distress and dismay about their children's worsening problems. As parents struggled with these tensions they began to slip and lose balance. When parents finally received the confirmed diagnosis of AS for their children, their experiences were transformed. A door was opened to understanding their children, to resources and supports, and to strategies for effective parenting. Over time, parents began to regain their balance and confidence in parenting. They were able to nurture their children's growth and development toward adulthood, albeit one that continued to be influenced by the unpredictable nature and associated limitations of AS. In recognizing the limits of their children's condition, parents learned to change and adapt their parenting style to varying degrees to accommodate their children's differences. Parents were indeed the experts, however, their expertise was hard won.

Overall, this study is a clarion call to health and school professionals, educators, and researchers to develop increased knowledge and understanding of AS, improve early identification of AS, and strengthen services and supports provided to parents of children with AS. The condition of AS is not isolated to childhood and adolescence but persists into adulthood, and, as a result, parents will be in need of continued support into their children's adult years.

Although AS is considered to be the mildest expression of the autism spectrum disorders (Dillon, 2007) it is associated with significant challenges that impact individuals with the condition, parents, and the family as a whole. The findings of this study demonstrate how parents continue to experience challenges in receiving a timely diagnosis of AS for their children, and accessing the services and supports they need. Thus, understanding the nature of parenting a child with AS has direct relevance to clinical practice, and merits further research attention. Above all, it is never too late to begin shining the spotlight more strongly on this important topic, and strengthening the care provided to parents of children with AS.

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APPENDICES
APPENDIX I: DSM-IV Diagnostic Criteria for AS
(APA, 1994)

A. Qualitative impairment in social interaction, as manifested by at least two of the following:

1. Marked impairment in the use of multiple nonverbal behaviours such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction
2. Failure to develop peer relationships appropriate to developmental level
3. A lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest to other people)
4. Lack of social or emotional reciprocity

B. Restricted, repetitive and stereotyped patterns of behaviour, interests, and activities, as manifested by at least one of the following:

1. Encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus
2. Apparently inflexible adherence to specific, non-functional routines or rituals
3. Stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole-body movements)
4. Persistent preoccupation with parts of objects

C. The disturbance causes clinically significant impairment in social, occupational, or other important areas of functioning.

D. There is no clinically significant general delay in language (e.g., single words used by age 2 years, communicative phrases used by age 3 years).

E. There is no clinically significant delay in cognitive development or in the development of age-appropriate self-help skills, adaptive behaviour (other than in social interaction), and curiosity about the environment in childhood.

F. Criteria are not met for another specific Pervasive Developmental Disorder or Schizophrenia.

APPENDIX II: Sampling Criteria

Inclusion Criteria:

- Parent(s), including mothers and fathers, of male and female children with AS who are between the ages of 11 and 19 years.
- Have known the diagnosis for at least 2 years and a maximum of 6 years.
- Can easily communicate (read and speak) in English.
- Currently live in or near Kelowna, Vernon, or Salmon Arm.
- Willingness to participate in the study.

Exclusion criteria:

- Child with AS has concurrent diagnosed medical and/or psychiatric conditions or comorbidities such as epilepsy, diabetes, non-verbal learning disorder, attention deficit hyperactivity disorder, depression, anxiety, and psychosis.

APPENDIX III: Letter of Introduction and Invitation to Participate in Study

THE UNIVERSITY OF BRITISH COLUMBIA | OKANAGAN



Faculty of Health and Social Development
Fine Arts and Health
3333 University Way
Kelowna, B.C. Canada V1V 1V7

Dear Parent(s),

This is a letter of introduction to tell you about a research project on parents' experiences raising a child with Asperger's Syndrome. This research is being done for a graduate degree at the University of British Columbia-Okanagan, and is funded by the Canadian Institutes of Health Research. To better support parents raising a child with Asperger's Syndrome, we need more knowledge and understanding of their experiences. Understanding what parents experience will help professionals better meet the needs of families in the community who are raising a child with Asperger's Syndrome.

You are invited to participate in a study that will explore your experience of raising a child with Asperger's Syndrome. Participating in this project would involve the completion of one demographic form to gather background information, and at least two face to face interviews. Each interview will last 1-2 hours long. The interviews will be completed at a time and place convenient to you. You will not be identified in any reports of this research. Participation in the study is completely voluntary and you may choose to withdraw at any time without any consequence to yourself or your family. Please find enclosed a copy of the consent form for you to review.

If you have any questions, or would like to give your name and contact information directly to the project researcher, please contact Kaley York by phone: 250-826-2940, or via e-mail: kaley24@interchange.ubc.ca. I look forward to hearing from you.

Thank You in advance for considering this request.

Sincerely,

Kaley York
Master's of Science in Nursing Student
University of British Columbia – Okanagan

APPENDIX IV: Consent to Contact Form

THE UNIVERSITY OF BRITISH COLUMBIA | OKANAGAN



Faculty of Health and Social Development
Fine Arts and Health
3333 University Way
Kelowna, B.C. Canada V1V 1V7

Project Title: An Interpretive Inquiry of Parents' Experiences Raising a Child with Asperger's Syndrome

This is to inform you of a research study on parents' experiences raising a child with Asperger's Syndrome. This research is being done for a graduate degree, and is funded through the Canadian Institutes of Health Research. We are requesting your permission to contact you with more information regarding this study.

The purpose of the research is to learn about what parents experience in raising a child with Asperger's Syndrome. The ultimate goal of this research is to improve services to parents raising a child with Asperger's Syndrome. We are interested in speaking with parents of male and female children between 11 and 19 years with Asperger's Syndrome. Interviews will be in-person at a time and place of your convenience.

At this time, we are asking only for your permission to be contacted to hear more about the study. We ask that you please sign and return this form and we will respond accordingly. If you indicate that you would like to be contacted, we will provide you with more details about the study, at which time, you can make a decision about your participation in the study. Your participation in this study is entirely voluntary. You may refuse to participate or withdraw at any time without any consequence to you or your family.

For more information about the study, please contact:
Kaley York
Master's of Science in Nursing Student, UBC Okanagan
Tel: XXX-XXX-XXXX

If you have any questions about your rights as a research subject, please call the UBC Okanagan Office of Research Services, 250-807-8832.

Please tick one of the following:

- I would like to receive more information about the study.
- I would not like to receive more information about the study.

Parent Name (please print)

Signature

Phone Number

Date

**Please return form by mailing the stamped envelope enclosed to: Kaley York, 3333
University Way, Kelowna, BC, V1V 1V7**

APPENDIX V: Advertisement

**Are you the parent of a male or female
child with Asperger's Syndrome who is
between 11 and 19 years of age?**

Researchers from the UBC Okanagan are interested
in talking with you about your experience.

**TO LEARN MORE ABOUT THIS RESEARCH
PROJECT**

Call and leave a message with your contact
information at XXX-XXX-XXXX or by email
kaley24@interchange.ubc.ca



APPENDIX VI: Draft Interview Guide

- Opening: Thank You for your interest in my research, and your time in meeting with me today. I am doing research on parents' experiences of raising a child with Asperger's Syndrome. I have prepared a list of questions that I would like to ask you to learn more about your experiences. There is no right or wrong answer to any of the questions. If you do not feel comfortable answering a question please let me know and we can move on to the next question. Your participation is voluntary and we can stop the interview at any time you wish for a break or to end the interview. I will be recording the interview. Is this okay? Do you have any questions before we start?
- I'm interested in what it is like to be the parent(s) of a child with Asperger's Syndrome. Can you tell me what it is like for you?
- When did you first begin to notice that your child had a difference? What happened after that?
- Tell me about receiving your child's diagnosis of Asperger's Syndrome? Do you have any questions or concerns about whether your child's diagnosis was correct?
- Since the time your child was diagnosed until now, what have been the major challenges you have experienced? Can you tell me more about these challenges? Have the challenges changed or stayed the same? Have some challenges become easier or harder?
- What has helped you get through the challenges? What has gotten in the way or made things harder?
- What are the positive aspects that stand out the most for you in raising [your child; or name]? Can you tell me more about these positive aspects?
- What has been the impact of having a child with Asperger's Syndrome on you? On your marital relationship/relationship with partner? What has the impact been on your family? (if applicable) On the sibling(s)? (if applicable)
- What services have you accessed? What has your experience been like accessing services? Did you experience barriers in accessing services?
- What did you find most useful in the services you received? What did you find the least useful in the services you received?
- What would you like to see from service providers?
- What would you recommend to other parents of children with AS?

- Closing: What stands out the most for you from this interview? Is there a question I should have asked you today that I didn't think to ask? Is there anything you would like to add?
- Thank You for your time and the ideas you have shared with me today.

APPENDIX VII: Demographic Form

Date: _____

ID #: _____

1. In what year were you born? _____

2. Gender: Male Female

3. How would you describe your ethnic or cultural identity? _____

4. Marital Status: Married/Common-law Widowed Divorced/Separated
 Single, never married

5. What is your highest level of education?

- Less than high school
- High school
- Technical and non-university education (college; CEGEP)
- University (undergraduate, bachelor's degree)
- University (graduate, master's degree, doctorate degree; post-doctorate degree)
- Other (specify) _____

6. What do you consider to be your main activities (please specify as many as are important to you)?

- Caring for family
- Working for pay
- Going to school
- Recovering from illness / on disability
- Looking for work
- Unemployed and not looking for work
- Retired
- Other (specify) _____

7. What was/is your usual occupation or profession? _____

8. Number of children in family:

List:	<u>Children</u>	<u>Gender</u>	<u>Age</u>
	_____	_____	_____
	_____	_____	_____
	_____	_____	_____

In consideration of your child who has been diagnosed with Asperger's Syndrome, please answer the questions below:

9. What is your child's birth position? (Example: 1st of 2 children)
_____ of _____ children?

10. What is the gender of your child (check one)?
 Male Female

11. How old was your child when he/she was diagnosed? _____

12. How old is your child now? _____

13. What is your relationship to the child (check one)?
 Mother Father Other (please specify) _____

14. In what community do you live? _____

15. What community services do you use to support the care of your child with Asperger's Syndrome?

16. What is your best guess of your household income in last year from all sources before taxes were taken out?

- Under \$11,000
- \$11,000-25,000
- More than \$25,000-50,000
- More than \$50,000
- Don't know/prefer not to answer

**APPENDIX VIII: Sample Format for Recording Fieldnotes
(Modified from Morse & Field, 1995, p.115)**

Participant Code # _____

Interview Date _____ Starting Time _____ Ending Time _____

Pre-interview goals for interview _____

Location of interview _____

Description of environment (including personal belongings) _____

People present _____

Content of interview (e.g., key words, topics, focus, exact words, or phrases that stand out) _____

Nonverbal behaviour (e.g., tone of voice, posture, facial expressions, eye movements, forcefulness of speech, body movements, and hand gestures) _____

Researcher's impressions (e.g., discomfort of participant with certain topics, emotional responses to people, events, or objects) _____

Analysis (e.g., researcher's questions, tentative hunches, trends in data, and emerging patterns) _____

Researcher reflexivity (e.g., personal influence, reactions, biases) _____

Technological problems (e.g., lost 5 minutes when tape turned) _____

APPENDIX IX: Informed Consent Form

THE UNIVERSITY OF BRITISH COLUMBIA | OKANAGAN



Faculty of Health and Social Development
Fine Arts and Health
3333 University Way
Kelowna, B.C. Canada V1V 1V7

Title of Project: An Interpretive Inquiry of Parents' Experiences Raising a Child with Asperger's Syndrome

Principal Investigator:

Dr. Carole Robinson, School of Nursing, University of British Columbia-Okanagan, 250-807-9882

Co-Investigator(s):

Kaley York, Graduate Student, School of Nursing, University of British Columbia-Okanagan, XXX-XXX-XXXX

Dr. Ed Taylor, School of Social Work, University of British Columbia-Okanagan

Andy Doyle, School of Nursing, University of British Columbia-Okanagan

Sponsor: This study is funded by the Canadian Institutes of Health Research Frederick Banting and Charles Best Canada Graduate Scholarships-Master's Award.

Background and Purpose of the Study

This study focuses on parents' experiences raising a child with Asperger's Syndrome. You are invited to voluntarily participate in this research study because you are the parent of a child, between 11 and 19 years of age, who has Asperger's Syndrome. You have known the diagnosis for between 2 to 6 years, and you live in or near Kelowna, Vernon, or Salmon Arm. The purpose of this study is to understand what it is like to be a parent of a child with Asperger's Syndrome.

Study Procedures

Your participation will involve completing a demographic form to collect background information, and a minimum of two face to face interviews. The interviews will be conducted at a time and place that is convenient to you. The total time commitment of your participation will be 1-2 hours for each interview. You will be asked questions about what it is like to raise a child with Asperger's Syndrome. A third interview will be available in case any further information is needed.

The interviews will be recorded and transcribed by the graduate student, Kaley York and possibly a research assistant. Interviews will be reviewed and analyzed to describe parents' experiences raising a child with Asperger's Syndrome.

Potential Risks

Minimal risks are expected from participation in this study. It is possible that some individuals may be uncomfortable talking about their experiences. You can stop talking and only start again if you wish. If you want to talk another time, we can schedule the interview again. A list of supports for parents of children with Asperger's Syndrome will be provided at the end of the first interview. There is no cost to you for participating in this study. There are no procedures or tests being conducted in this study.

Potential Benefits

A possible benefit for you may be sharing your experiences. You will have the chance to talk about this topic with an interested nurse. You may also experience some good feelings from being part of this study because it may help improve the services provided to parents of children with Asperger's Syndrome.

Confidentiality

Your name will not be associated with the recorded interviews or typed transcripts. A code number will be used to identify all documents. The information will be stored in a locked file cabinet and computer files will be password protected. Only research staff and team members associated with this project will have access to the data. You will not be identified in any reports of this research. Information from this study may be used again for further research on parents' experiences raising a child with Asperger's Syndrome. Information collected in this study may also be used for teaching purposes without revealing any information that identifies you. This study is for a graduate degree and information from this study is part of a thesis (public document).

Remuneration

For your participation, each family will receive a \$25 gift certificate to Safeway. This honorarium is not dependent on completion of the study. If you withdraw before completion you will receive a pro-rated amount.

Consent

Your participation in this study is voluntary. You may refuse to participate or withdraw at any time without any consequence or explanation. By signing this consent form, you agree to participate in this study and confirm that you have received a copy of this consent form for your own records. By signing this consent form, you do not waive any of your legal rights.

If you have any questions or desire further information, you can contact Dr. Carole Robinson at (250) 807-9882 or email to carole.robinson@ubc.ca or anyone on the research team.

If you have any concerns about your rights or treatment as a research subject, you may contact Kristen Kane, Manager of UBC Okanagan Behavioural Research Ethics Board in the UBC Okanagan Research Services Office at (250) 807-8832 or e-mail to kristen.kane@ubc.ca.

I have read the above information and I have had a chance to ask any questions about the study and my involvement. I understand what I have to do and what will happen if I take part in this study. I freely choose to take part in this study, and I have received a copy of the consent form.

Participant's Signature

Date

Witness Signature

Date

Contact for Future Studies:

Would you be willing to be contacted in the future about other studies?

- Yes, I would like to receive information about follow up studies on parents' experiences raising a child with Asperger's Syndrome
- Yes, I would like to receive information about future studies on Asperger's Syndrome
- No, I would not like to receive information about future studies.

Participant Signature: _____

Date: _____

If you choose to participate in this study, please indicate if you would like to receive a research summary and your contact information.

___ I would like to receive a research summary at the address listed below:

APPENDIX X: Supports for Parents of Children with AS

1. Family physician

2. Counselling services

a) Kelowna:

- Stepping Stones Counselling Group, Contact Vicki Cairns, Registered Clinical Counsellor, at 250-763-7414
- ACCESS Resources, Behavioural and Educational Support Services Team (BESST) program providing individualized services and support to families of children with autism spectrum conditions, Contact Opal Blackhall, Program Director, at 250-763-2217
- Psychologist, Contact Dr. Bill Maniago at 250-864-4847 or Dr. Lisa Young at 250-826-9766

b) Vernon:

- Psychologist, Contact Dr. Kevin Murphy at 250-260-4470 or Dr. Jane Wakefield at 250-542-4046

c) Salmon Arm:

- Psychologist, Contact Dr. Susan Johnson at 250-832-6633

3. Parent Support Group

- Autism Support Kelowna, Contact Dayna Tarr-Robertson at 250-763-7488