THE EXPERIENCE OF MOTHERS AND CLINICIANS IN THE ASSESSMENT OF AUTISM SPECTRUM DISORDER

by

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Abstract

Being told that their child meets criteria for a diagnosis of Autism Spectrum Disorder (ASD) is life-changing news for parents. Prior to the diagnosis, they wait and worry and are faced with uncertainty about their child. After receiving the diagnosis, parents must adjust to the loss of “normalcy” and the demands of arranging services. In Canada, psychologists are regularly involved in conducting assessments and communicating the diagnosis of ASD to parents. Despite research examining parents’ experience with the diagnostic process, few studies have additionally considered clinicians’ perspectives and practices in conducting ASD assessments.

In the present study, the experiences of mothers and clinicians before, during, and after a diagnosis of ASD were examined. The aim was to better understand how parents present when coming to an assessment for ASD, their reaction to the diagnosis, and the support they and their child received. This had the potential to provide insight into effective ways to meet the needs of parents as they process and attempt to move forward with their child’s diagnosis of ASD. In the present study, semi-structured interviews were conducted with mothers and clinicians from lower mainland British Columbia. Data was categorized and analyzed using an inductive approach to thematic analysis. From the mother interviews, twelve themes emerged to depict experiences across the phases of assessment, while fourteen themes were revealed through clinician interviews. Findings revealed that mothers suspected ASD before the assessment began, clinicians made attempts to be clear and compassionate, and that information regarding resources was sufficient yet overwhelming for parents. In general, mothers were satisfied with the
clinician and assessment approach yet discontent with the understanding and support received from outside sources.
Preface

The graduate student, under the supervision of the research supervisor, conducted the present study. Content of this thesis is based on original unpublished work conducted by Anna Bowers with supervision from Dr. Laurie Ford. The graduate student and research supervisor collaborated to develop the research design and recruit participants. The student was primarily responsible for the data analysis and writing components of the present student. Therefore, this thesis is representative of the graduate student’s work as co-investigator and lead author. The research conducted as part of this study was approved by the University of British Columbia Behavioral Research Ethics Board (BREB) under certificate number H13-03510.
# Table of Contents

Abstract .............................................................................................................................. ii  
Preface ............................................................................................................................... iv  
Table of Contents ............................................................................................................... v  
List of Tables .................................................................................................................... viii  
List of Figures .................................................................................................................. ix  
Acknowledgements .......................................................................................................... x  
Chapter 1: Introduction ................................................................................................. 1  
  Overview ......................................................................................................................... 1  
  Definition of Key Terms ............................................................................................... 1  
Chapter 2: Review of the Literature ........................................................................... 3  
  Autism Spectrum Disorder ............................................................................................ 3  
  Raising a Child with ASD ............................................................................................. 8  
  The ASD Assessment Process ....................................................................................... 11  
  Summary ......................................................................................................................... 17  
Chapter 3: Method ........................................................................................................ 18  
  Overview ......................................................................................................................... 18  
  Purpose of the Study ..................................................................................................... 18  
  Research Questions ....................................................................................................... 18  
  Theoretical Framework ................................................................................................. 19  
  Procedures ....................................................................................................................... 19  
  Participants ..................................................................................................................... 22  
  Ethical Considerations ................................................................................................. 23
## List of Tables

Table 1. Characteristics of Mother Participants.............................................................................. 23
Table 2. Characteristics of Clinician Participants............................................................................. 23
Table 3. Example of Data Segments and Codes................................................................................. 29
Table 4. Summary of Mother Perspectives......................................................................................... 49
Table 5. Summary of Clinician Perspectives....................................................................................... 67
Table 6. Summary of Strengths & Challenges..................................................................................... 75
Table 7. Putting Findings Into Practice................................................................................................. 88
List of Figures

Figure 1. Mother Thematic Map for Phase 1 ................................................................. 38
Figure 2. Mother Thematic Map for Phase 2 ................................................................. 44
Figure 3. Mother Thematic Map for Phase 3 ................................................................. 48
Figure 4. Clinician Thematic Map for Phase 1 ............................................................... 52
Figure 5. Clinician Thematic Map for Phase 2 ............................................................... 56
Figure 6. Clinician Thematic Map for Phase 3 ............................................................... 63
Figure 7. Clinician Thematic Map for Phase 4 ............................................................... 66
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Chapter 1: Introduction

Overview

Autism Spectrum Disorder (ASD) is a neurodevelopmental condition that encompasses impairments in social interaction and communication, and repetitive or restricted behaviour (Keenan, Dillenburger, Doherty, Byrne, & Gallagher, 2010). The child’s difficulties can have a significant impact on the family, resulting in stress, isolation, and stigma as well as feelings of uncertainty (Mulligan, MacCulloch, Good, & Nicholas, 2012). In the last 40 years, the prevalence of ASD has increased drastically (Solomon & Chung, 2012). Statistics from the United States Centers for Disease Control and Prevention (2014) identified around 1 in every 68 children as affected by ASD, with 4 of 5 diagnosed children being male. This has rendered ASD one of the most common developmental disabilities (Fombonne, 2003). More and more families are being faced with the task of seeking an assessment and adapting to a diagnosis of ASD. The assessment process for ASD has been found to be difficult for parents, who are simultaneously managing their child’s symptomology and dealing with its impact on family quality of life (Siklos & Kerns, 2007; Solomon & Chung, 2012). Limited research within a Canadian context has examined the experience of both parents and clinicians in an ASD assessment. The congruence between giving and receiving the diagnosis and support is therefore not well understood. A better understanding could reveal practices that address the strengths, demands, and needs of families when making a diagnosis of ASD and developing a treatment plan.

Definition of Key Terms

Developmental Disability. The term developmental disability describes life-long impairments that are attributable to mental and/or physical disabilities (Developmental
Disabilities Association, 2013). There are a variety of developmental disabilities with ASD, cerebral palsy, and Down’s syndrome being the most common. Children with a developmental disability do not meet, or are delayed in meeting, expected milestones (Coleman, 2006).

**Autism Spectrum Disorder.** This developmental disability is a lifelong neurodevelopmental disorder that encompasses a core triad of deficits involving social interaction, communication, as well as restricted or repetitive behaviours (American Psychological Association (APA), 2013). There are varying degrees of impact, and impairment in functioning can improve, worsen, or change throughout the lifespan (Dua, 2003).

**Developmental Assessment or Evaluation.** This term refers to a detailed investigation of a suspected developmental delay (Saulnier & Ventola, 2012). The evaluation may lead to a diagnosis, treatment plan, rule-out, or suggestions for further assessment if necessary (Dworkin, 1993). For the purposes of the present study, the term assessment will be used to refer to the developmental evaluation that was conducted to determine if a diagnosis of ASD was warranted.

**Mother.** The British Columbia (BC) Ministry of Education defines a parent as “a) the guardian of the child; b) the person legally entitled to custody of the student or child; or c) the person who usually has the care and control of the student or child” (BC Ministry of Education, 2001). The participants in this study were all women who fit this definition, and were the primary caregivers and most involved during their child’s assessment.

**Clinician.** This term will be used to refer to credentialed health professionals responsible for conducting clinical diagnostic assessments for ASD. In the context for this study, this term applies to psychologists who are registered with the College of Psychologists of British Columbia and had training in the assessment of ASD.
Chapter 2: Review of the Literature

Autism Spectrum Disorder

**Definition.** Autism Spectrum Disorder (ASD) is a lifelong neurodevelopmental disorder that affects the way a person understands and relates to the world around them. The qualitative impairments in social interaction, verbal and nonverbal communication, and flexibility of thoughts and behaviours prevent children with ASD from developing typical cognitive and social skills (Koplewicz et al., 2004). Children with ASD commonly have a comorbid intellectual disability, language or learning disability, or psychiatric disturbance (Dua, 2003). As a developmental disability, ASD can affect children in a variety of ways and to various extents (Wall, 2010). Practitioners are presented with a different set of characteristics and severity of symptoms each time they assess a child for ASD. “Withdrawal” is also commonly seen in this population, given their apparent disinterest in the world around them and lack of desire to participate in everyday interactions with others (Wall, 2010). This presents a significant barrier for parents as they attempt to enter the world of the child, and for clinicians as they seek to understand the child while helping to prepare parents to address the needs of their child.

**Prevalence.** Until the mid-1990s, ASD was considered a rare disorder, however, estimates of its prevalence have risen dramatically over the past 15 years (Kogan et al., 2009). Consistent with increased rates in North America, British Columbia has witnessed a significant rise in the last two decades in the number of children identified with ASD, with the current prevalence estimated as 1 in every 88 children (BC Ministry of Children and Family Development, 2013). It remains unclear what factors have contributed to this increase in
identification, with some believing it is due to a broader definition, changes in diagnostic criteria for ASD, and/or heightened awareness of the disorder (Wall, 2010).

**Causes.** The complex profile of children with ASD has resulted in various theories as to the cause of this developmental disability. While the way in which biochemical and other features typically associated with ASD lead to the disorder remains unclear, genome-wide identification of genetic deletions and duplications have pointed to their causal role (Simonoff, 2012). Twin studies have identified a limited influential role of environmental risk factors (Szatmari, 2003). Recently, the way in which epigenetic factors play a role in the expression of ASD has gained attention. Flashner and colleagues (2013) suggest that dysfunction of epigenetic regulation (i.e., when genes are incorrectly switched off or turned on) may play a crucial role in the etiology of ASD. Others have proposed that the slowdown in the brain “pruning” process that typically occurs during development results in a surplus of synapses in the brain, which in turn has significant effects on brain functions (Columbia University Medical Centre, 2014). The dismissal of claims that ASD is caused by poor parenting practices has brought relief and the tempering of guilt for parents (Wall, 2010). On the other hand, the numerous and conflicting messages received by parents about causes for their child’s atypical profile renders the assessment and diagnostic process an emotionally intense time encompassed by feelings of both hope and confusion (Mulligan et al., 2012). Clinicians making the diagnosis play a critical role in helping parents understand and “digest” what is contributing to their child’s diagnosis.

**Leading up to the diagnosis.** Children referred for an ASD assessment are likely to have had symptoms that emerged after a period of typical development. A combination of features, including a limited ability to engage in play, lack of communicative gestures, limited imitation
skills, and atypical intonation, typically emerge at around 18 months of age (Chawarska et al., 2014). Red flags that appear in later childhood include disinterest in sharing enjoyment or interacting with others, inappropriate eye contact, hypersensitivity to sensory stimuli, and spinning objects or hand flapping (Wall, 2010). It has been proposed that early detection and diagnosis minimizes the distress that is often experienced within the family as a result of dismissed concerns or delayed seeking of an assessment (Barbaro & Dissanayake, 2009).

**Diagnostic criteria.** While the origins of ASD are likely neurobiological in nature, behavioural symptomology is required for a diagnosis to be warranted. The current diagnostic criteria as outlined in the *Diagnostic and Statistical Manual, Fifth Edition* (DSM-5; APA, 2013) fall under the category Autism Spectrum Disorder. A diagnosis of ASD is given no matter where on the spectrum the child’s level of functioning is located. There are no longer category subtypes (i.e., Autistic Disorder, Asperger’s Disorder) as was the case in the previous edition of the DSM. The behavioural features of ASD fall within the following symptom categories: (1) persistent deficits in social communication and social interaction; and (2) restricted, repetitive patterns of behaviour, interests, or activities (APA, 2013). A diagnosis of ASD requires onset of symptoms in early childhood, even if not fully manifested until social demands exceed the child’s level of social functioning (Autism Speaks, 2015). While there is more heterogeneity than similarity in ASD symptomology across children, clinicians attempt to uncover a common pattern in the child’s ability to navigate their social world. Further understanding is needed with regards to the challenges that clinicians face when determining the extent to which a child meets criteria, and how they subsequently attempt to guide parents in processing and understanding the unique profile of their child.
Legislation and guidance. Given that this research study took place in British Columbia (BC), it is important to outline the initiatives that have guided autism services in BC. The dramatic increase in rates of identification, and the need for systematic and consistent diagnostic procedure and service provision for children with ASD, prompted shifts in the social policy, funding allocation, and health care initiatives in the province. In 1998, the Autism Action Plan (AAP) was introduced by the Ministry for Children and Family Development (MCFD), the Ministry of Education, and the Ministry of Health. This document and the AAP-Implementation plan made recommendations in four categories: 1) early intervention and treatment; 2) assessment, diagnosis, and eligibility; 3) education and training; and 4) transition to adult services (BC Ministry of Children and Family Development and Ministry of Education, 1999).

In 2002, the BC government responded to the variability and inconsistency in the diagnostic process for ASD by inviting a group of multidisciplinary professionals in the province to work on devising the Standards and Guidelines for the Assessment and Diagnosis of Young Children with Autism Spectrum Disorder. The document became policy for the BC Ministry of Health and continues to guide all diagnostic assessments for ASD in BC, whether they are conducted through the British Columbia Autism Assessment Network (BCAAN) or a private specialist (MCFD, 2013). This project aimed to ensure that assessment and diagnostic services for ASD in children under the age of six are consistent, adhere to best practices, and are sustainable and practical (Dua, 2003). The working group established a clinical pathway, recommendations for developmental surveillance and ASD specific screening tools, a timeframe for primary care investigation and referral, and requirements for assessment and diagnosis (Dua, 2005). The BCAAN was created in 2001, made up of specialists and health care professionals
who aim to provide timely assessment and diagnostic services while following the standards and
guidelines set by the BC Ministry of Health. Little is known about clinician’s perceptions of
working within these standards and guidelines, specifically the extent to which they are feasible
and enhance efficiency and flexibility. It is important to better understand whether parents
continue to have concerns in areas that have attempted to be addressed.

**Purpose and procedure of the assessment.** One of the primary factors in parents’
decisions to obtain an assessment for ASD for their child is to be eligible for funding and
additional support services. The Autism Funding Programs developed by the BC Ministry of
Children and Family Development (MCFD) are currently available for children who have
received a BCAAN or private assessment and diagnosis of ASD. The Autism Funding: Under
Age 6 program provides families with up to $22,000 per year to assist in purchasing autism
intervention services and therapies. The Autism Funding: Ages 6 to 18 program provides
families with up to $6,000 per year to assist with the costs of services both outside and within the
school (MCFD, 2013). While some families have responded positively to the freedom to choose
interventions, others believe the funds to be inadequate for the required intensity of treatment
their child required, have difficulty accessing qualified professionals, or find the responsibility of
decision-making to be overwhelming (Dua, 2005).

In BC, a tiered approach is applied for the early identification, assessment, and diagnostic
procedure. Given that there are no biochemical or neurological markers, a diagnosis must rely on
clinical decisions based on observations of the child’s behavior and parent reports of current and
historical information about the child (Filipek et al., 1999). The first step typically involves
general developmental surveillance of children in community settings (Bradley, 2010). If results
suggest that ASD is likely, a detailed clinical diagnostic assessment involving an interview and observation takes place, followed by a comprehensive multidisciplinary assessment (i.e., psychological assessment; speech-language assessment; medical evaluation) (Lord et al., 1997). Thus, a multidisciplinary team of professionals may assess a child across several sessions, or a developmental pediatrician, psychologist, or psychiatrist may see the child for a single assessment visit (Mulligan et al., 2012). Results from the ASD clinical diagnostic assessment are then integrated with the findings from the multidisciplinary assessments before a diagnosis of ASD is made (Dua, 2003). The present study focused specifically on the clinical diagnostic assessment component, which involved the psychologist administering a comprehensive interview and observation, as well as cognitive measures and rating scales. Experiences of the final meeting in which findings, the diagnosis, and next steps were discussed was also considered to better understand parents’ reactions and feelings in response to the diagnosis and guidance offered by the clinicians in terms of setting up support services.

**Raising a Child With ASD**

Parents of a child exhibiting ASD characteristics often experience greater psychological distress than parents of a typically developing child (Bromley, Hare, Davison, & Emerson, 2004; Siklos & Kerns, 2006) or even a child with another developmental disability (Dabrowska & Pisula, 2010). Through interviews and rating scales, Bromley and colleagues (2004) examined mothers’ social support and mental health. Results indicated perceptions of limited access to services, and associations both between low levels of family support and high levels of parent distress, as well as between high levels of child emotional disturbance and high levels of parent distress. In another study examining concerns and needs as a result of caring for a child with
ASD, Whitaker (2002) found that parents were keen to respond to their child’s worrying and puzzling behaviours yet unequipped to begin the assessment process. The 18 mothers interviewed in their study tended to seek information as opposed to emotional support. Results indicated that they were unsuccessfully striving to develop intuition, empathy, and ultimately a sense of “connectedness” with their child. Consistent with these findings, Mulligan and colleagues (2012) interviewed parents of children with ASD with results indicating feelings of confusion and being emotionally overwhelmed as a result of their own and others’ concerns and suspicions, as well as dismissal by others in an attempt to decrease the parent’s worry. Cashin (2004) also considered the meaning parents attribute to caring for a child with ASD and the way in which this role evokes change to the parent’s self. Interviews and focus groups revealed that less spontaneity and social contact resulted in a sense of a dominating parenting role and shrinking of self thereby forcing parents into a restricted and repetitive pattern of daily living. Parents in this study reported that the parenting role had overridden other roles and involvements, and that they were forced to assume complete focus on helping their child. They described a feeling of urgency in trying to do everything to help their child as quickly as possible. Considering the threat that ASD can have on a family’s sense of connectedness to society, Woodgate et al. (2008) interviewed parents of children with ASD with results indicating that they were experiencing isolation from a “normal” way of life and from the world in which their child lives. Parents reported that they believed society lacks an understanding of what autism is and what caring for a child with ASD entails. Findings from these studies suggest that clinicians are in an important position to address parents’ feelings of difference and not being
understood, and to bring awareness at the time of diagnosis to resources and support that can facilitate connection and participation in society.

Prior research has explored factors that contribute to healthy adaptation to parenting a child with ASD. Higgins and colleagues (2005) had 135 caregivers complete a survey to identify protective factors for parents experiencing lower family functioning as a result of caring for a child with ASD. These were found to include high self-esteem, optimism, positive reframing, and spousal support. Another study found that a balance between a sense of personal control over the child’s disorder and feeling supported by others contributed to fewer symptoms of depressed affect by parents (Dale et al., 2006). In a quantitative study, Siklos and Kerns (2006) had 56 parents complete the Family Needs Questionnaire and found that receiving social support from community programs, professional help, and services led to healthy adaptation to having a child with ASD. Woodgate et al. (2004) reported that working toward a healthy balance, cherishing milestones, and learning to let go served as strategies in sustaining a sense of self and family for the families they interviewed. A positive outlook on parenting a child with ASD was also uncovered by King et al. (2006) through focus groups of parents and service providers. Parents reported that raising a child with a disability necessitates a reappraisal of the family’s belief system as well as enhanced coherence and control.

These findings suggest that parenting a child with ASD is without a doubt challenging and is encompassed by frustration due to difficulty connecting with their child and isolation. However, parents also demonstrate incredible resiliency through a shift in beliefs and perceptions, and focusing on the child’s strengths and meeting their needs. It has been well established that the developmental differences and needs of a child with ASD symptomology
results in a range of potential impacts on the family system. Where research is lacking is with regards to clinician perceptions and responses to the emotional state of parents when they come for an ASD assessment. This understanding has the potential to uncover clinical skills and practices that develop hope and bring attention to resources that aim to meet the needs of both parents and children with ASD.

**The ASD Assessment Process**

**Before the diagnosis.** Various factors prompt parents to seek an assessment for ASD. Sikos and Kerns (2007) found parents’ preliminary concerns to often focus on the child’s language and social development (Siklos & Kerns, 2007). Research indicates that 80% to 90% of parents reported their first concerns about their child’s development by the time they were one- to two-years-old (Chawarska, et al., 2009). However, it is typically not until the child is 5- to 6-years-old, after having seen an average of 4.5 professionals, that a formal diagnosis of ASD is given (Howlin & Moore, 1997; Siklos & Kerns, 2007). While some parents are fairly confident that their child has ASD and feel the need for a confirming diagnosis (Wall, 2010), others have no preliminary concerns or none specific to ASD (Braiden, Bothwell, & Duffy, 2010).

Parents interviewed in the study by Mulligan and colleagues (2012) reported that their suspicions of ASD led them to spend considerable time seeking out information and learning about the disorder through books and the Internet. The dismissal by family, friends, educators, and health care providers of parents’ concerns was reported to result in feelings of frustration and exacerbated confusion. In semi-structured interviews with 11 mothers of children with ASD between the ages of 7 and 11, Braiden et al. (2010) investigated parents’ experience of the diagnostic process and found that caregivers reported that they had difficulty adequately
explaining their concerns to their general practitioner. This is consistent with findings of a lack of receptivity on the part of professionals when parents first raise concerns (Goin-Kochel, Mackintosh, & Myers, 2006; Harrington, Patrick, Edwards, & Brand, 2006).

Siegel (1996) identified two purposes served by a diagnosis of ASD that often motivate parents to seek an assessment. One is to obtain a diagnosis that signifies that the child exhibits a recognizable problem for which a treatment plan can be developed and implemented, and the other is to act as a ticket to services. While a diagnosis of ASD does not always secure the provision of appropriate services, it should ideally help inform the decision-making process (Wall, 2010). The literature also indicates that a diagnosis provides validation for some families. Thus, some parents seek a diagnosis with the hope of extricating ambiguous and conflicting messages, understanding and coming to terms with their child’s difficulties so as to move forward and make life more manageable (Avdi, Griffin, & Brough, 2000a; Mulligan et al., 2012).

**Who diagnoses.** Through a diagnostic survey examining the issues faced by BC families in obtaining a diagnosis of ASD for their child, Siklos and Kerns (2007) found that most parents received the final diagnosis of ASD from a clinical psychologist (30.9%), a pediatrician, or family doctor (30.9%). Others obtained the diagnosis from a child psychiatrist (13.2%) or a multidisciplinary team (19.1%). While 58% of families reported that the professional who made the final diagnosis was in their city, 42% had to travel to another city for the meeting to discuss the results. Families in the study saw an average of 4.46 professionals throughout the course of the diagnostic process. While BCAAN aims to facilitate timely assessment and diagnosis in close proximity to the family, it is unclear whether families in BC remain confused and frustrated with the timeline, options of settings and professionals, and a range of appointments.
**The role of parents.** Parents play a critical role throughout the assessment and diagnostic process of ASD for their child. Dunst and colleagues (2011) suggest that when clinicians involve parents in the collection and dissemination of information throughout the assessment process, a family’s capacities are strengthened. “Capacity-building help-giving practices,” as termed by Trivette and Dunst (2007), involves practitioners acknowledging the concerns and priorities of parents while identifying supports and resources that can be drawn upon in moving forward following disclosure of their child’s diagnosis. Thus, there is a reciprocal interaction in which the perspectives and needs of parents are a focus and considered important in gathering information for the assessment.

With regards to the feedback meeting in which results and perhaps a diagnosis are disclosed to parents, some believe parents should be seen as lay diagnosticians or clinicians (Arksey, 1994), while others believe parents are experts in their own rights and should be consulted (Avdi, Griffín, & Brough, 2000b). Still others apply the relational model in which the diagnosis is shared in a way that offers opportunity for joint meaning-making (Rigazio-DiGilio, 2000). It is important to better understand how clinicians are encouraging parents to express feelings, reactions, concerns, or questions as well as how parents experience the final meetings in terms of feeling listened to, included, and valued.

**Perceptions of the diagnostic process.** The behaviourally based diagnostic criteria combined with the unknown etiology, invisibility of some symptoms, and spectrum-based nature of ASD results in an assessment and diagnostic process that can be difficult for parents to navigate and make them susceptible to clinician doubt as compared to an evaluation for other developmental disabilities (Mulligan et al., 2012). While early identification of and intervention
for ASD has positive outcomes for a child, parents have reported experiencing significant hardships obtaining a diagnosis (Chung, Smith, & Vostanis, 1995; Konstantareas, 1990; Nissenbaum, Tollefson, & Reese, 2002; Siegel, 1996). Given the impact of a delayed diagnosis on the child’s functioning, clinicians experience pressure to conduct efficient yet comprehensive assessments. This, however, may run the risk of reaching premature or incorrect conclusions (Braiden et al., 2010).

Much of the literature on parent experiences of an assessment for ASD has pointed to dissatisfaction with various factors involved in the assessment process. For example, long wait times and vague diagnoses (Howlin & Moore, 1997), a lack of acceptance of initial concerns (Brogan & Knussen, 2003), insufficient information pertaining to ASD (Sikos & Kerns, 2007), insufficient advice and opportunities for follow-up (Keenan et al., 2010), and clinician characteristics (Braiden et al., 2010). Recent research by Mulligan and colleagues (2012) conducted in Toronto, Canada through interviews with parents uncovered perceptions of the final meeting as frustrating and one-sided with little opportunity to ask questions or delve into what the diagnosis means. Chamak and colleagues (2011) found that parents’ dissatisfaction stemmed from the blunt delivery of the diagnosis without care or consideration for their feelings of guilt and shock. In a similar study, parents reported that they were generally positive about the feedback session and the professional involved, although described experiences of information overload and prolonged emotional impact after the session (Abbott, Bernard, & Forge, 2013).

These findings highlight the importance of clinicians engaging and empowering parents throughout the assessment process. Information is lacking with regards to how both clinicians and parents experience the collaborative process of understanding the meaning of the diagnosis.
and how to navigate treatment services. This has important implications for clinical skills that promote a sense of assuredness, control, and competence so parents feel supported and are equipped to meet the needs of their child.

**Reaction to a diagnosis of ASD.** Considerable research has examined parents’ reactions to a diagnosis of ASD in their child, with parents reporting a range of feelings from anger and uncertainty to relief, validation, and empowerment (Mulligan et al., 2012). When Hutton & Caron (2005) invited parents to talk about their reactions to their child’s initial diagnosis of ASD, some caregivers reported experiencing grief, loss, shock, and self-blaming upon hearing the news. However, for many parents, it has been found to be validating and reassuring, reporting that the diagnosis allowed them to understand that the child’s behavior was related to characteristics of ASD rather than consequences of their parenting approach (Mulligan et al., 2012). Similarly, parents have expressed relief, as indicated through comments that they finally obtained a label that made sense (Hutton & Caron, 2005). Feelings of frustration and isolation, exacerbated by ambiguous and conflicting messages, were alleviated for parents as a result of a diagnosis that offered an “antidote to uncertainty” (Avdi et al., 2000a). These findings suggest that the way in which a diagnosis is delivered and how suggestions for follow-up are made have an important impact on parents’ mental and emotional state when they walk away from the feedback meeting.

Parents face a unique set of challenges that impact their ability to successfully process, accept, and adapt to a diagnosis of ASD (Hastings et al., 2005; Wachtel & Carter, 2008). This often depends on the degree to which a parent has resolved their feelings associated with receiving the diagnosis, a concept that Pianta and Marvin (1993) termed “resolution of
diagnosis.” For parents, their acceptance of the diagnosis, incorporation of the diagnosis into their reality, and resistance of self-blame will determine the extent and rate at which this resolution is achieved. Research on family response and adaptation to a child’s diagnosis of ASD has found active avoidance, which involves the creation of distractions from a stressful situation, to be associated with stress, anxiety, and depression symptoms in parents (Hastings et al., 2005). On the other hand, problem-focused strategies, which involve attempts to reframe the nature of the problem, do not appear to induce these symptoms. Interestingly, parents of children with ASD have been found to employ escape-avoidance coping strategies more frequently than parents of typically developing children (Pisula & Kossakowska, 2010).

The importance of clinicians attending to parental emotions and cognitions associated with the diagnosis was demonstrated by Wachtel and Carter (2008) who found that parents who were unable to resolve distressing emotions and changes in their family’s situation as a result of the diagnosis had more difficulty being attuned and responsive to their child’s needs. Research findings have indicated that parents find the use of service agencies to be one of the most successful strategies for processing and adapting to their child’s diagnosis of ASD (Gray, 1994). Despite an increased focus on positive factors that facilitate coping in parents, it remains unclear how professionals can develop or enhance factors such as acceptance, autonomy, and purpose in parents of children they diagnose. Further research is needed to consider strategies that are being used by clinicians and perceived as helpful by parents when communicating a diagnosis of ASD. This is important for uncovering clinical practices that help parents process emotions and enhance their readiness to move forward with treatment provision for their child.
Summary

This review of the literature provides a framework for further examining the experience of the diagnostic process for ASD for mothers and clinicians. Going through an assessment for ASD has been found to evoke a range of feelings for parents, facing unique challenges that impacted their psychological adjustment once they left the clinician’s office with the diagnosis (Wachtel et al., 2008). Little is known about the views of parents regarding support and guidance offered by clinicians throughout an ASD assessment, nor is it well understood how clinicians have been attempting to help parents as they process and move forward with the diagnosis. The primary purpose of the current study was to explore the support and guidance that mothers received or would have found helpful, and clinicians’ perceptions of how they supported and guided parents during ASD assessments. By seeking to understand the perspectives of both mothers and clinicians, this study aimed to uncover clinical skills and strategies that help families adapt while minimizing the stress and challenges typically experienced when receiving a diagnosis of ASD.
Chapter 3: Method

Overview

The aim of this study was to explore and better understand the assessment process for ASD from the perspective of mothers whose child had been diagnosed with the disorder as well as clinicians who conduct ASD assessments. To achieve this aim, semi-structured interviews were used as the main data collection method and thematic analysis was applied to determine themes emerging from the data. In this chapter, the design of the study, including its purpose, research questions, theoretical framework, procedures, ethical considerations, data collection, and data analysis is presented.

Purpose of the Study

The purpose of this study was to examine the experience of clinicians and mothers as they participate in an assessment for ASD and attempt to make meaning of the diagnosis. Perceptions of various stages of the assessment process were uncovered, as well as similarities and differences between perceptions of strengths and challenges of the two groups of participants. This study addressed the ASD assessment process in British Columbia, Canada specifically in order to better understand the way in which the unique ASD diagnostic procedure in that province was being conducted and received.

Research Questions

1. What are mothers’ purported experiences of pursuing an ASD assessment and receiving a diagnosis for their child?
2. What do clinicians perceive as their role in conducting an ASD assessment and conveying diagnostic information?
3. What are the consistencies and discrepancies between mothers’ and clinicians’ perceptions of strengths and challenges in the assessment process for ASD?

**Theoretical Framework**

A social constructivist epistemology was selected due to its capacity to report the experiences, meanings, and realities of participants that are effects of interactions in society (Braun & Clarke, 2006; Hays & Singh, 2012). Constructivism assumes that the meaning individuals come to attribute to their experiences is socially produced and reproduced. The sociocultural contexts and structural conditions are examined to understand the individual accounts provided (Braun & Clarke, 2006). Researchers and participants hold biases and have voices that are reflective of their own cultural experiences and developed identities (Hays & Singh, 2012). Rather than objectively labelling events and beliefs being indicated through participant reports, an examination of behaviours and narratives reveals perceptions related to the experience under investigation. In terms of the present study, examining mothers’ and clinicians’ experiences of an ASD assessment was thought to have the potential to uncover interactions and perceptions that contribute to the meaning-making process when a diagnosis of ASD is received.

**Procedures**

**Selection.** Inclusion criteria for participation in the study were established before the recruitment process began. Practical and technical reasons impacted the participant selection criteria. The criteria for mother participants were:

1. Child was diagnosed with ASD between the ages of 2 and 6. Given that a diagnosis of ASD can be made at any age, the researcher thought it best to have parents with similar initial concerns and children in similar stages of development.
2. Child was diagnosed within the previous 12 months from when the interview was conducted. This was to enhance the likelihood of parents accurately recalling the assessment procedure and the interactions and emotions that they experienced.

3. The mother was English-speaking. This was due to the researchers’ lack of proficiency in languages other than English, and lack of access to interpreters. It was believed that interpretation prevents an accurate depiction of the participant's experiences revealed through interviews.

4. The mother lived in lower mainland British Columbia. This was meant to ease interview logistics and ensure that participants experienced an ASD assessment in accord with the BC Ministry of Health.

Participants in the clinician group had to meet the following criteria:

1. Health care professional competent in conducting assessments for ASD.
2. English-speaking.
3. Lived in lower mainland British Columbia.

**Recruitment.** A clinician information letter (see Appendix C) was sent by email to clinicians in lower mainland BC who were listed on the BCAAN and the BC College of Psychologists websites. A psychiatrist in lower mainland BC who the researcher knew also sent out the letter to paediatricians and child psychiatrists that conducted ASD assessments. From these initiatives, one clinician expressed interest in participating and was sent a copy of the clinician consent form (see Appendix E) and a time and date was set up to conduct the interview. Additional clinician respondents were identified by a snowball technique in which the initial participant passed along the study invitation letter to colleagues who conducted ASD
assessments. Participants were recruited through this method until there was an exhaustion of sources and sufficient data was collected.

Initiatives taken by the researcher to recruit parents involved contacting the administrators of various agencies providing services to children with ASD to describe the purpose and nature of the study. The researcher inquired about putting up a recruitment poster (see Appendix A) in the waiting room that identified who is eligible to participate, the purpose of the study, what participating would involve, and contact information to receive a parent information letter (see Appendix B) and/or copy of the parent consent letter (see Appendix D). Due to a lack of response from this method, networking was also conducted to recruit parents. A contact of the researcher passed along the researcher’s contact information to a family friend with a child diagnosed with ASD. This mother expressed interest and the information letter and consent form were emailed, and time and date for the interview was set up. A snowball technique was used to seek additional parent participants, by which the initial mother informed fellow members of a Facebook group for parents in Vancouver with a child with ASD of the study. This recruitment method was pursued until saturation was reached and sufficient data was collected.

In the end, snowball sampling was the primary recruitment strategy for both clinicians and parents. As described by (Faugier & Sargeant, 1997), a series of referrals within a circle of people who know each other facilitates access to hard to reach populations. In the case of this study, parents of children with special needs often experience high caregiver demands and stress, and clinicians have limited availability due to their busy schedules. An attempt was made to access participants with varying demographic characteristics and who were acquaintances, as opposed to close friends, of other participants.
Participants

Consistent with studies using similar methodology, the present study involved a small number of participants to facilitate an in-depth portrayal of experience and allow for the complexity of experiences to be revealed and thoroughly understood (Smith, Humphreys, & Wilson, 2008; Smith, 2011). This facilitated closely defined groups for whom the research questions were significant and from which results had applicable implications within the broader context (Smith, 2003).

Three mothers and five clinicians participated in the study. Initiatives were made to recruit both mother and father participants, but seeing as mothers passed along information about the study to other mothers, the study ended up having a female parent sample. However, attempts were made to obtain information pertaining to their spouse’s experience of the ASD assessment as well. All clinicians were Registered Psychologists conducting ASD assessments in private practice settings, although many had previously worked in government funded settings. None of the clinicians were involved professionally with any one of the mothers who participated in the study, nor did the mothers obtain an assessment at the settings in which the clinicians worked. Demographic information of participants is provided in the tables that follow. Codes were assigned to each participant to protect their confidentiality.
Table 1.  
**Characteristics of Mother Participants**

<table>
<thead>
<tr>
<th>Code</th>
<th>Age</th>
<th>Highest Level of Education</th>
<th>Employment Status</th>
<th>Other Children in the Home</th>
<th>Child’s Age When Diagnosed</th>
<th>Who Made Diagnosis</th>
<th>Type of Support Currently Received</th>
</tr>
</thead>
<tbody>
<tr>
<td>P1</td>
<td>40</td>
<td>College (Spouse: College)</td>
<td>Part-time (Spouse: Full-time)</td>
<td>Younger sibling</td>
<td>3 years, 5 months</td>
<td>Psychologist</td>
<td>Home-based behaviour intervention Consultant ABA</td>
</tr>
<tr>
<td>P2</td>
<td>36</td>
<td>College (Spouse: High School)</td>
<td>Part-time (Spouse: Full-time)</td>
<td>Older sibling</td>
<td>3 years, 10 months</td>
<td>Psychologist</td>
<td>Strong Start School SLP School OT/PT Respite (for parent)</td>
</tr>
<tr>
<td>P3</td>
<td>42</td>
<td>Graduate Degree (Spouse: Graduate Degree)</td>
<td>Part-time (Spouse: Part-time)</td>
<td>None</td>
<td>5 years, 9 months</td>
<td>Psychologist</td>
<td>Private SLP Private OT/PT Tutoring Social skills curriculum</td>
</tr>
</tbody>
</table>

ABA=Applied Behaviour Analysis; SLP=Speech-Language Pathologist; OT/PT=Occupational/Physical Therapist

Table 2.  
**Characteristics of Clinician Participants**

<table>
<thead>
<tr>
<th>Code</th>
<th>Age</th>
<th>Highest Degree</th>
<th>Primary Work Setting</th>
<th>Years in Field</th>
<th>Years Assessing ASD</th>
</tr>
</thead>
<tbody>
<tr>
<td>C1</td>
<td>58</td>
<td>PhD (School Psychology)</td>
<td>Schools/Private Practice</td>
<td>11</td>
<td>7</td>
</tr>
<tr>
<td>C2</td>
<td>45</td>
<td>Master of Arts (School Psych)</td>
<td>Private Practice</td>
<td>15</td>
<td>7</td>
</tr>
<tr>
<td>C3</td>
<td>62</td>
<td>PhD (Clinical Psychology)</td>
<td>Private Practice</td>
<td>30</td>
<td>25</td>
</tr>
<tr>
<td>C4</td>
<td>50</td>
<td>PhD (Clinical Psychology)</td>
<td>Private Practice</td>
<td>20</td>
<td>20</td>
</tr>
<tr>
<td>C5</td>
<td>33</td>
<td>PhD (Clinical Psychology)</td>
<td>Hospital/Private Practice</td>
<td>14</td>
<td>12</td>
</tr>
</tbody>
</table>

**Ethical Considerations**

Various factors were considered to ensure a high level of ethical rigour in conducting this research. Ethics approval was obtained through the Behavioural Research Ethics Board (BREB) at the University of British Columbia. Since the identity of participants was made known to the
researcher through face-to-face interviews, a number was assigned to each participant to protect their identity. This number was indicated on transcripts and demographic questionnaires to identify participants. A list of participant names and contact information, as well as the code used for that participant, was kept separate from data collection materials in a password-protected file on secure computers. All study documents including transcripts from the interviews were kept in a locked filing cabinet in the research lab of the study supervisor at the University of British Columbia. Audio recordings of the interviews were saved through password protection on the computer and subsequently deleted from the recording device. These files were only accessible by research team members.

Informed consent was obtained from participants before beginning the initial interview. A summary of the study purpose and procedure was provided prior to participation, as well as notification that consent could be withdrawn at any point of the study. Contact information of the student researcher and supervisor was provided as was the number of the university research office should the participant have questions or concerns about rights or the study itself.

**Data Collection**

**Overview.** The techniques used for data collection in this study were semi-structured interviews and a reflective journal kept by the student researcher. A total of nine interviews were held in parent homes, public locations, over telephone, and in agencies and hospital settings. Perceptions, reflections, and questions were gathered and documented by the researcher through a journal immediately following each interview. The researcher visited each site one or two times, with all interviews conducted over approximately two months, to complete the data collection process.
**Semi-structured interviews.** In clinical and educational research, semi-structured interviews are a way of gathering information that is not easily accessible through methods such as observations or surveys (Tierney & Dilley, 2002). Open-ended interviews facilitate in-depth description, exploration, and explanation of participants’ experiences (Mulligan et al., 2012). This approach also allows the voice of participants to be heard and understood while providing a richer picture of the phenomena under investigation (Hays & Singh, 2012).

The mother interviews conducted in this study invited participants to reflect on and describe their experience with the ASD assessment process while also exploring the meaning, events, and processes related to receiving the diagnosis and preparing to move forward with treatment planning. All mothers participated in one or two interviews ranging from 60 to 90 minutes, depending on the rate at which topics were explored.

The clinician interviews invited participants to reflect on and describe their experience conducting ASD assessments. Interview questions were aimed at exploring the meaning, events, and processes related to supporting and guiding parents as they receive the diagnosis of ASD and begin to think about resources for their child and family. It is noteworthy that clinician interviews explored working with *parents* as opposed to perceptions around *mothers* specifically. All clinicians participated in one interview lasting approximately 60 minutes.

At the beginning of each interview, the consent form was reviewed with and signed by participants. A copy was given to mothers and clinicians for their records and the researcher kept the original. The participants were asked to complete the parent background questionnaire (see Appendix F) or clinician background questionnaire (see Appendix G). The researcher then conducted the interview, posing questions that focused on exploring the experience of an ASD
assessment. The interview guide for mother and clinician interviews can be found in Appendix H and Appendix I, respectively.

Interviews were audio-recorded to facilitate flexibility in questions and responses. The researcher reviewed the audio recording following each interview to ensure that all questions had been sufficiently covered. In the event that follow-up questions were thought necessary to discuss, an additional interview was set-up. The researcher transcribed the interviews once the data collection process was completed.

**Reflective Journal.** The researcher kept a journal to document experiences in conducting the study. Thoughts, problem solving, decision-making points, insights, and follow-up items were recorded after each interview session. Reactions to the events, emotions, and thoughts disclosed by participants were recorded as well as novel, interesting, or particularly relevant issues that emerged. This provided a greater context for interpreting interview data and allowed the researcher to become aware of any personal biases infiltrating into the role as interviewer.

**Data Analysis**

**Method.** The aim of the analysis was to identify and explore ideas and themes that emerged in the interview data, leading to an enhanced understanding of the thoughts and experiences of clinicians and mothers as they relate to an ASD assessment and the meaning-making process involved in moving forward with a diagnosis of ASD. The method used for analyzing interviews was thematic analysis, as outlined by Braun and Clarke (2006). This widely used qualitative analytic method involves “thematizing meanings” (Holloway & Todres, 2003, p. 347) by searching for themes or patterns across the data set as well as within a data item such as individual interviews (Braun & Clarke, 2006). One reason why this approach was used in the
present study was its flexibility since it could be applied across a range of theoretical and epistemological approaches (Braun & Clarke, 2006). Thematic analysis is also compatible with the social constructivist paradigm applied in this study, and provided a procedure through which rich, detailed, and complex accounts of the data were uncovered. Roulston (2001) advises caution when applying this method to interviews since researchers may view participant statements as reflections of reality and what is “out there” rather than considering the theoretical notion of “reflexivity” and viewing remarks as interpretations of processes. When a critical eye is cast, thematic analysis offers the researcher a tool for reducing, reorganizing, and categorizing data in themes that capture something important in relation to the research questions or that is prominent across the data set (Braun & Clarke, 2006; Roulston, 2001). While other approaches to data analysis were considered, thematic analysis was deemed to be the most in line with the goals and design of the present study. For example, thematic analysis allowed for prominent themes to be uncovered and described so as to reveal participants’ perceptions of particular experiences, as opposed to developing a theory about those themes such as in grounded theory (Thomas, 2006). Discourse analysis was deemed not applicable to this research design given that the study was not aiming to describe multiple meanings of language and text. Lastly, phenomenology was ruled out seeing as the intent of the study was not to reveal people’s everyday experience of reality in great detail so as to understand a phenomenon in question (Braun & Clarke, 2006; McLeod, 2001).

**Process.** Thematic analysis was conducted with data from interviews with mothers and clinicians. Each data item was analyzed with the aim of identifying themes that capture something important about the experience of participating in or conducting an ASD assessment.
That is, a rich description of the entire data set was uncovered that in turn captured predominant patterns of the experience discussed. Themes were identified that were reflective of the data and research questions as opposed to theoretical or analytical interests or interpretations of the researcher. Recorded observations and comments in the reflective journal were used to further conceptualize statements made in the interviews. The phases of thematic analysis were carried out using the step-by-step guide described by Braun and Clarke (2006):

**Phase 1.** Transcription of the interview data into written form began the process of becoming familiar with the data following the interview. The interpretative act of transforming content from spoken to written form allowed for the preliminary emergence of meanings within the data (Lapadat & Lindsay, 1999). Through this process, and subsequent repeated readings of the transcriptions, a thorough understanding of the depth and breadth of interactions and content was gained. The transcriptions were printed and the researcher engaged in close readings of each text. Notes were made in the margins to identify segments of text that were noteworthy in terms of prevalence or relevance to research questions.

**Phase 2.** The researcher then went through the data from the first parent interview and manually created In Vivo codes (i.e., key words found verbatim in the data), which were written in the margins. These codes identified features of the data that appeared interesting and relevant to the analyst. The researcher consulted the reflection journal throughout this phase to bring attention to statements that were highlighted as novel or interesting. Upon referencing the reflection journal, no documented comments that revealed potential biases in data interpretation were noted. The codes and their accompanying segments of data were copied into a Microsoft Word document. See Table 3 for an example of text segments and corresponding codes.
Table 3.
Example of data segments and codes

<table>
<thead>
<tr>
<th>Data Extract</th>
<th>Coded For</th>
</tr>
</thead>
<tbody>
<tr>
<td>Even though everyone else around me was saying like he’s fine, he’s fine, he’s fine I’m like shut up. Like don’t say that. I’m his mother and I have genuine concerns and stop trying to placate my feelings. (Parent)</td>
<td>“Genuine concerns”</td>
</tr>
<tr>
<td>Often the parents are pretty sure and I’d say 80% of the time they’re right so it’s a bit tough when they’re not…when the answers they’ve gotten don’t fit with what they know about their child. (Clinician)</td>
<td>“Answers don’t fit”</td>
</tr>
</tbody>
</table>

After codes were applied, the data set was organized into meaningful groups. This was done by collating together extracts that depicted the same code in the word document thereby forming code groupings. This process of creating codes for individual text segments was then conducted for subsequent mother interviews, with identified codes copied into the corresponding grouping in the document. Once initial codes were created and grouped for all parent interviews, codes for clinician interviews were generated through the same procedure.

**Phase 3.** Once all data was coded and codes were collated based on similarity, an analysis at a broader level of themes began. This consisted of sorting codes and corresponding data excerpts to form overarching themes. Themes are described by Braun and Clarke (2006) as capturing something important about the research questions and represent a patterned response or meaning within the data. To determine what constituted a theme, considerations were made pertaining to (1) prevalence across data sets (i.e., the number of interviewees who displayed evidence of the theme), (2) the extent to which the theme captures something important in relation to the research questions, and (3) researcher judgement (Braun & Clarke, 2006). The process of identifying themes involved copying codes and exemplary text segments in another document, followed by the researcher playing around with organizing them into ‘theme piles’
(Braun & Clarke, 2006, p. 89). This experimental sorting procedure allowed for conceptualization of relationships between codes, themes, and themes at different levels (e.g., overarching versus sub-themes). To further identify themes and understand connections between them through visual representation, thematic maps were created as suggested by Braun and Clarke (2006). Mother and clinician thematic maps for each phase of the assessment process allowed for further consideration of emerging themes and subthemes, as well as the similarities and differences between themes of participant groups.

**Phase 4.** Reviewing and refining of the devised themes involved identifying candidate themes that were not themes (e.g., insufficient supporting data), collapsing themes into each other, or breaking themes into separate themes (Braun & Clarke, 2006). This was to ensure that themes worked together in meaningful ways and that they were distinguishable. Extracts for each theme were reviewed to ensure they captured the contours of coded data, and were each considered in relation to the data set. The thematic maps were then revisited to determine if all themes were accounted for or if some refinement needed to occur. This phase also involved collaboration between the researcher and the research supervisor as well as two research assistants to ensure consistency in coding and theme identification.

**Phase 5.** The report of findings (Chapter 4) was organized into twelve broad themes for mothers and fourteen broad themes for clinicians. Themes were defined separately with the aim of identifying the “story” that each depicts about the data in relation to the research questions. Citations depicting each theme were included to facilitate analysis at an interpretative level and provide a clear depiction of the scope of each theme.
**Cross-Group Analysis.** Data from each mother and clinician interview was first analyzed separately. Once codes and themes were identified for each group of participants, a comparative analysis was conducted in which similarities and differences between themes of the groups were established. Consideration was given to the application of broad themes, subthemes, and specific content to either or both groups of participants. This allowed for their experiences to be compared and contrasted, and revealed how the groups perceived each other as well as whether parents believed clinicians to be practising what they claim. Findings pertinent to each group, and comparisons between results found for the groups, are described in Chapter 4.

**Triangulation and Validity**

In the context of qualitative research, validity ensures that findings depict participants’ narratives of what happened (Jupp, 2006) while triangulation is a strategy to demonstrate the validity and reliability of findings (Roulston, 2010). In an attempt to reduce systematic bias, data was triangulated by gathering information from parents and service providers, and using interviews and a reflective journal (King et al., 2006). Elements of the interview transcripts were checked against entries in the reflection journal to identify any inconsistencies or missing concepts. The transcripts were checked against the original audio recordings to ensure accuracy. Regular meetings between the researcher and research supervisor facilitated inter-rater reliability through discussion, reflection, and re-checking the accuracy of data analysis. Consistency in theme labelling was also ensured through checking procedures with two research assistants. This involved providing the research assistant with a random selection of data segments and having them identify the corresponding theme on the thematic maps. Consistencies and discrepancies in theme labelling were discussed, followed by review and refining of the themes.
Chapter 4: Findings

Overview

The purpose of this study was to gain a better understanding of the experiences of mothers as their child underwent an assessment for ASD, how clinicians perceived their role in the assessment process, and the strengths and challenges of parents and clinicians during the assessment.

The findings in this chapter are summarized by the themes identified by the researcher as contributing to the exploration of the research questions guiding this study. The themes for each participant group are described, followed by a comparison across groups of perceived strengths and challenges. Themes are discussed according to phase in the assessment process.

Perspectives of Mothers

Mothers shared rich and detailed descriptions of events, thoughts, and feelings related to the ASD assessment for their child. They described a lengthy and complex process from when they first began having concerns to when they got the diagnosis and were tasked with putting together a treatment plan. Approximately 40 initial themes were identified within the mother interview data. This was narrowed down to twelve themes that were categorized according to phase in the assessment process. Three to five themes, and associated subthemes, were identified for each phase. These emergent themes are discussed below with detailed descriptions of themes and corroborating text quotes to reveal the patterned responses and meaning within the mother interview data. See Table 4 for a summary of phases, themes, and subthemes.

Phase 1: Before the Assessment

Through descriptions of the ASD assessment process, the mothers in this study described what was going on for them, their child, and their family before the assessment began. Mothers
reported experiencing a variety of emotions when attempting to “get their head around” their child’s difficulties, the possibility of it being ASD, and how to seek answers. Mothers also described reactions of others during this period. Their experiences before the assessment were grouped into five broad themes and five subthemes, which are each discussed below. See Figure 1 for a visual organization of themes in this phase.

**Theme 1. Something’s not right: Is it me? Is it a phase?** Long before a formal diagnosis was made, mothers knew their child’s behaviour was “different” or “quirky.” They reported knowing that “something was up” and feeling a need to look into this further. The label “ASD” did not jump to their mind initially, but rather mothers indicated that they were confused as to why their child was failing to engage with others. Feelings of confusion stemmed from comparisons to other children, being unable to console their child, and being “put through the ringer” on a daily basis when they did not know why their child was behaving that way. One mother’s confusion was demonstrated through the statement, “I was terrified. I was like, is it me? Is it something I’m doing? Am I overreacting? Is this going to be a phase? Is he going to snap out of it?”

Mothers also revealed that they were helpless as to how to cope with and manage their child’s abnormal behaviour. Some mothers reported that nothing was getting easier or that help could not be sought because no one understood what they were dealing with. As another mother explained, “You have all these hopes and dreams for your child, for their future, and they were just pretty much all shattered.” Overall, mothers described a gut instinct that their child’s functioning was atypical, which in turn evoked confusion and exhaustion from feeling as though there was nothing they could do to help themselves or their child.
Theme 2. Suspicions: Is it autism? All mothers reported having no knowledge of ASD when they first believed that something was not quite right with their child’s social functioning. Their confusion led them to seek information online. One mother decided to do some reading online which led her to complete questionnaires asking about ASD-related behaviours. As she explained, answering “yes” to several items and having the website tell her to get her child checked out made the “gut feeling that something was up” a reality and a significant source of worry. Another mother described that the worsening of her child’s symptoms evoked anxiety, which led her to read up on ASD and in doing so she started to think, “It could be autism. It could be autism.” Thus, researching ASD and related symptoms online led to enhanced knowledge of the disorder, which caused mothers to become increasingly convinced that this was what was going on for their child. Mothers described the outcome of researching ASD as “looking at everything differently” and thinking “wow, yes, this could be a possibility.”

Theme 3. Isolation: Can’t go anywhere. Mothers consistently reported that their child’s meltdowns made it so they could not attend social engagements, or were required to leave early when their child was inconsolable. This left mothers feeling very frustrated because they had to stay home, and had experienced several failed attempts at connecting their child with peers. One mother stated that this “led to a real feeling of isolation and depression in some sense” and another described her reaction to the lack of connection with her child and others as, “Yup, this is my life.”

Theme 4. Response by others: No way or I think you are right. Mothers described the ways in which friends, family, and professionals reacted to concerns they voiced about their child or to observations of their child. While some mothers experienced validation of concerns
and suspicions of ASD, others were told not to worry or to wait it out. Mothers expressed a variety of reactions to these responses by others.

**Subtheme 4.1: Agreement with concerns.** The agreement of friends and family members with mothers’ concerns tended to be perceived as validation and encouragement to pursue help. One mother indicated that it evoked frustration, stating,

*Everybody was like: So you might want to sit down. I don’t want to upset you but I think your son might have autism. And I was just like: Why do you think I’m here? You’re upsetting me. I’m not upset.*

This mother did not want to be pitied or babyed when she already had the suspicion that her child had ASD. The overall desire of mothers appeared to be support in their belief that the child’s behaviour was concerning and that it should be looked into further.

Mothers also described the response of professionals when they first sought an explanation for what was going on with their child. One mother described the guidance she received from her child’s teacher in response to voiced concerns, stating, “She said, ‘Go to your paediatrician, get a referral, and get checked for ASD.’ And that’s kind of how we got going.” Having concerns validated by the family doctor was described by a mother who said,

*[The family physician] heard my concerns. She said, “I think you’re right. I’ve noticed these things and I will check it out…it sounds like we want to investigate.” So then we filled out some questionnaires. Then she looked them over and said, Yes, I’ll make a referral. There are too many things here that stand out.*

**Subtheme 4.2: Dismissal of concerns.** Mothers also talked about situations in which friends and family members dismissed their concerns about their child. A mother described her frustration and upset prompted by the reactions of friends and family, stating that:

*Even though everyone else around me was saying like, He’s fine, he’s fine, he’s fine. I’m like shut up. Like don’t say that. I’m his mother and I have genuine concerns and stop*
trying to placate my feelings…I need support in this decision. Not like, ‘Oh you’re just reading into things.’

Another mother had a different reaction to the response she got from others. Being told not to worry, that the child will grow out of it and it’s just her personality, caused the mother to believe that these people must know what they are talking about because they have more experience, and that she could put off seeking further help. The degree to which mothers were certain their concerns were in accord with what was truly going on with the child appeared to impact the extent to which they accepted or resisted others’ dismissal of an occurring problem.

**Theme 5. Waiting: Unable to get therapy started.** Mothers described significant periods of waiting before attending the first session of their child’s assessment for ASD. This waiting tended to occur between visits to various professionals to obtain a referral for an assessment to examine ASD, as well as between when the referral was made and the first assessment session. One mother described the steps she had to go through, indicating that it took 8 months to get her child’s hearing checked, 6 months to get a referral to see a paediatrician, and 7 months from that point to be seen by the psychologist at a government-funded assessment location. Throughout the waiting process, mothers described feeling increasingly agitated as a result of feeling the need to “get to the root of what was going on” for their child and feeling pressure to get treatment services in place as soon as possible.

**Subtheme 5.1: Already know it is ASD.** Mothers described frustration from having to wait to start the assessment when they were already confident that the outcome would be a diagnosis of ASD. As one mother explained, “I’m here for a reason, because I already have the belief [that it’s autism]…I don’t want to wait any longer.”
The strong beliefs and frustration voiced by mothers indicated that their sights were set on getting the diagnosis because it was thought of as “a ticket to services.” Waiting for that diagnosis was indicated to be a very difficult period because they were seeing their child struggle while struggling as a parent and having no way to obtain help without funding. One mother stated that she basically had to tell her child, “Sorry honey, you won’t be helped until [we get a diagnosis].” Another mother described her experience of being repeatedly told that early intervention is best, and knowing something was up, yet having to wait so long to get to the point where she could get her child’s therapy started.

**Subtheme 5.2: Wait-and-see.** The delay in getting started with the assessment was sometimes due to the physician telling the parents that there were not enough red flags to warrant a referral, and that they were to come back in a few months time to have the child seen again. Mothers perceived this reaction as a dismissal of their maternal instinct and an invalidation of their concerns. They had no choice but to follow the doctor’s directive and come back to see if their child’s behaviours had changed, which in turn only prolonged their feelings of worry and uncertainty.

**Subtheme 5.3: Reflections.** Mothers described things they wish they had done or known while waiting to begin their child’s ASD assessment. One mother explained,

_Had I listened to my gut instinct when I first thought about it, when he first started showing all these kind of red flags. That’s me just going, ‘Ugh I should’ve got this ball rolling.’ Like I didn’t realize how long the process would be and how many hoops I’d have to jump through and all the people I’d have to go through. Nothing’s ever easy. Nothing’s ever just like, ‘Oh I think this is what’s happening, so let’s figure it out.’_
Other mothers explained regret of accepting the initial dismissal by teachers or support workers that contributed to them delaying the process of seeking an assessment for their child. One mother stated that she “would’ve started the process earlier.” As another mother described,

*Once you’ve seen one kid on the spectrum, you’ve seen one kid on the spectrum. So for us, there was a bit of upset about saying it’s not autism...we might’ve lost a year of funding... the most anxiety came out of that for us.*

Overall, the experiences mothers described with regards to waiting for their child’s ASD assessment to begin indicated frustration and confusion from the numerous steps they had to pursue, and the length of time in between each step. While mothers believed that their child’s symptoms were in accord with ASD and were told that early intervention is critical, they were frustrated by not having control over when the diagnosis and funding would be granted.

**Figure 1.**

*Mother Thematic Map for Phase 1*
Phase 2: During the Assessment

Mothers described what the assessment process was like, from the intake interview to the meeting in which results were shared. This was reported to take place over the course of two to three sessions during which the parent interview, child observation, testing, and feedback took place. A review of mothers’ experience of this phase revealed their perceptions of the clinician who conducted their child’s assessment, what it was like to get the diagnosis, and the support needed and received as they went through this stressful and life-changing process. Mothers described their experiences under four broad themes and seven subthemes, which are each discussed below. See Figure 2 for a visual organization of themes in this phase.

Theme 1. Getting the diagnosis: Validating but evoked worry. Mothers described the final meeting with the psychologist, in which the results and diagnosis were communicated, as generally positive. Coming into the meeting, they reported being prepared for the diagnosis and confident about what the psychologist was going to say. Mothers hoped their child would get the diagnosis because they suspected abnormal behaviour, and believed that only ASD could explain it while also knowing that the diagnosis would make them eligible for funding. This anticipation also stemmed from the worry of not receiving a diagnosis of ASD and being left with challenges and uncertainties yet ineligible for support.

Subtheme 1.1: Reaction. One mother described feeling like “an enormous weight lifted off [her] shoulders of not knowing what’s going on.” Others indicated that it confirmed their fears and what they already knew in their heart was going on, or a reinforced confidence that they knew their child. Receiving the diagnosis for their child was perceived as a justification for their efforts and choices up until that point and a feeling of relief that they “hadn’t screwed them
up.” However, mothers also reported feeling some anxiety because of the long road ahead with regards to seeking funding and intervention services.

**Subtheme 1.2: Meaning.** Mothers attributed both positive and negative meanings to receiving the diagnosis of ASD for their child. Mothers indicated that the diagnosis signified challenge and patience, as well as pressure and diligence. These meanings were partly in response to the intense support their child required to address ongoing behaviour challenges, and feeling as though anything less than 100% effort on their part would result in their child regressing. A mother explained how the child’s challenges create challenges for her as the parent, explaining, “Everything is much harder for him and other people won’t see that so they’ll expect normal things from him, which for him will be incredibly hard, and that breaks my heart.”

Other mothers described the diagnosis as meaning possibilities, specifically, knowing how to support their child, and opening doors to get funding so the child can have one-on-one attention and intervention. A positive perspective was also evident through a statement that the diagnosis was “for [the child’s] betterment. For her to be able to grow and thrive, and be a part of society.” A feeling of reduced isolation was also mentioned, as well as enhanced harmony within the family and a hope that they can go out and have fun doing things together.

**Theme 2. Different beliefs than husband: Can’t deny the challenges.** All mothers reported that the assessment process was hard on their marriage. This was primarily a result of differing perceptions from their spouse regarding the child’s functioning and behaviour management. Mothers described their reactions to these differing beliefs, and enhanced congruence in perceptions as the assessment went along.
**Subtheme 2.1: Certainty or denial.** All mothers stated that their husband denied that the child was experiencing significant difficulties, believing that they will go away or overestimating the child’s social skills and behaviour. One mother reported, “He just didn’t see it the way that I did,” attributing this to the lack of research done by her husband. Another described questioning whether her husband had “blinders on, like my kid’s perfect, there’s nothing wrong with him.”

**Subtheme 2.2: Contention.** Most mothers described conflict that ensued as a result of different stages in acceptance of their child’s ASD characteristics. This was exemplified by the following description of a mother’s experience attempting to get her husband to understand her point of view.

*We fought a lot. There was a point of contention in our relationship for a good two years... he was not having any of it... [I said,] ‘You can’t deny the challenges we face. You can’t just pass them off as a phase anymore.’ Like that just doesn’t fly with me.*

**Subtheme 2.3: Delayed acceptance.** All mothers reported that their husband did not think the child had ASD until the diagnosis was communicated in the results meeting. A mother reported having to go through the steps of pursuing an assessment on her own up until the end of the assessment when her husband came to terms with the atypicality of their child’s functioning.

**Theme 3. What the clinician did or said: Efficient and personable.** Mothers reported being generally satisfied with their psychologist’s approach throughout the assessment. They believed there was an adequate balance between addressing the difficulties of raising a child with autism, presenting the findings, exploring the meaning of the diagnosis, and providing practical tools and resources. Overall, mothers reported that since they were prepared for the diagnosis, they did not need or wish to be “babied” by the psychologist but rather wanted information about their child and tools to move forward and help them.
Subtheme 3.1: Checking-in. Mothers reported an appreciation for their clinician checking-in with them about how they were managing in their caregiver role, what they needed from them and in terms of support services, and whether they had questions or concerns about the findings and recommendations being presented. This contributed to mothers perceiving the clinician as empathic, that they “got her stuff done,” let the parents talk, and were tuned into what they were experiencing. One mother appreciated the thoroughness of the clinician’s approach, stating, “I felt like she took the time to really dig into this…feeling like this woman did all she needed to do and she didn’t gloss over us.” Another mother reported “feeling heard. Feeling like this doesn’t end today. She very clearly said, ‘If you have questions email me…we’ll talk.’” Consistent with this statement, a mother described her clinician checking-in by “asking, ‘what do you need? Do you have any questions?’ Like we never felt like we were being kicked out of the office. We really felt at the end like we were good, we can go. So that was important.”

Subtheme 3.2: Clear and factual. Mothers also reported an appreciation for their clinician providing assessment results in a clear and specific way, with descriptions of examples and how they map onto specific symptoms of ASD. One mother explained that the clinician was,

Straightforward. To the point. These are our findings. This is what we feel the child needs…they gave me all the tools. I left having all the tools I needed to move forward with it. You know, now the journey begins.

This approach led mothers to believe that the clinician covered everything and did not make generalizations. Appreciation was expressed for focusing on the provision of information in a factual manner as opposed to focusing on emotions and conveying sympathy.
Theme 4. Support received: Helpful but not enough. Mothers described sources of support sought and received while they were going through the assessment process. In most cases, ASD-specific treatment had not yet been pursued since funding had not yet been granted. The options for parent support were reported to be limited due to accessibility, availability, and not definitively knowing what was going on for their child. However, they indicated a desire and need for support to manage their child’s behaviour and navigate the assessment process.

All mothers were part of a Facebook group for mothers of children with ASD or exhibiting ASD characteristics. As one mother explained,

> The only support for myself was through support groups on Facebook...that’s probably been the most I would say helpful...I’ve actually found people on there that are quite knowledgeable and quite experienced...have been in the system for a few years.

Friends also offered support, particularly those who also had a child with ASD. One mother described meeting with a friend whose son had Asperger’s and asked, “Where do I go? What do I do? What are Behaviour Interventionists? What kind of OT do we need?” Just talking to a friend to unload their challenges and experiences was indicated as helpful.

Going through the assessment process evoked barriers and uncertainties for mothers. They described their experience connecting with other mothers to share their stories and gather advice and strategies as a way to confront and manage particular situations as well as to cope as a parent of a child with ASD symptoms. As one mother explained,

> Every time I get to like a hurdle I kind of go on my little group and ask, did anybody ever have this trouble with toileting where they have so much success and then they kind of regress? What happened? And then I got a flood of responses immediately, like these moms are just so on top of it.

Another mother described not knowing where to start with seeking an assessment, and going to her online support group asking for help. Mothers appreciated having other mothers
who listened and responded with empathy and practical tips, as well as being made to feel as though they were not alone in the challenges they were experiencing.

**Figure 2.**
*Mother Thematic Map for Phase 2*

**Phase 3: Moving Forward**

Mothers revealed what it was like get a diagnosis of ASD for their child and be tasked with applying for funding and setting up a treatment plan for their child. Leaving the psychologist’s office with a report in hand and a packet of information regarding resources was believed to be both motivating and overwhelming, particularly as they continued to process the diagnosis. Mothers described their experiences during the phase shortly after the results meeting with the clinician through three themes and four subthemes, which are each described below. See Figure 3 for a visual organization of themes in this phase.
Theme 1. Readiness to set-up treatment: Let’s get started or feeling numb. It became apparent that after the results meeting in which parents received the diagnosis and information pertaining to funding access and support services, some mothers were “ready to run” while others were still processing emotions and information, and were confused as to where to start. Some mothers were in “thinking or feeling mode” and needed time to adjust to what the label meant for their child and family. Others were in “operation mode,” motivated to get started with the funding application and seeking treatment so as to see improvements in their child’s and family’s functioning.

Subtheme 1.1: Just needed diagnosis. All mothers reported that they finally had what they waited months to receive: a diagnosis, which, to them meant a ticket to services. One mother described that, having already gone through the process of grieving for the loss of a typically developing child and coming to terms with the idea of having a child with ASD, she was ready to move forward when she got the diagnosis. Having no idea where to start did not seem to faze her. She was motivated by the urgency of starting intervention as soon as possible. Another mother found that sitting down and brainstorming treatment options and prioritizing what to focus on helped her to begin the process of setting up a plan to support her child.

Subtheme 1.2: Daunting and overwhelming. Some mothers described feeling exhausted after receiving the diagnosis, and needing time to process the results before beginning to access funding and services. As one mother explained, “I felt really numb…there were a few days where I was just like, ugh…just nothing. I didn’t feel anything. I just felt kind of bad and disorganized.” Seeking funding and putting together an intervention team was perceived as daunting in terms of figuring out what to do, the amount of work required as their new role as
“case manager,” and facing the long journey ahead in caring for their child. In some cases, the mothers felt that they had been provided with sufficient information in the form of pamphlets and packages, but that the psychologist “didn’t really go over how to get all of this stuff in place.” Following the results meeting, initiatives such as doing research, asking questions to other mothers of children with ASD, and being organized with the resources given, were thought to be helpful in moving forward with efficiently setting up services.

Theme 2. Hopes and fears: Being accepted and achieving milestones. In response to the social and communication deficits in addition to unusual behaviours exhibited by their children, mothers expressed hopes and fears they had for their child as they moved forward from the assessment. It became apparent that these pertained to their child’s treatment by peers, gains in the child’s functioning, as well as sufficiency and quality of support and services. One mother’s worry centered around “people thinking he’s selfish. He’s such a caring little guy so knowing people might not see him for who he is. That really upsets me.” With extensive effort on the part of mothers to pursue and adhere to an intense treatment program, they expressed concern and anxiety about their child “going backwards, not moving forwards…falling back on old habits…losing him again.” In anticipation of the child entering formal schooling, one mother was worried about whether her son would have enough support because she had been told that it would be shared. Losing control over the intensity, quality, and amount of help their child would receive in treatment settings other than the home was a source of worry for mothers.

Theme 3. Support: Availability and accessibility. Mothers discussed the support that their child has received since receiving a diagnosis of ASD, as well as any support they and their husband had received as parents. Insufficiencies in both forms of support, as well as challenges
in seeking and pursuing available options, were reported. It became evident that mothers were
grateful to have answers regarding resources and funding, yet frustrated, confused, and on their
own when it came to putting a treatment plan into action.

**Subtheme 3.1: What’s available.** Mothers sought behaviour interventions for their child,
and for the most part had positive experiences with interventionists and saw improvements. One
mother worked with a junior consultant who administered the therapy. It was important to the
mother that she chose her team and the programs used, and regularly reviewed her child’s
progress and goals. The only service another mother sought for her child was a government-
funded preschool program, but this was terminated due to the child’s anxiety and homeschooling
was the only feasible option. Another mother was pursuing occupational therapy, social skills
programs, and a behaviour interventionist for outings in the community. Hesitancy to seek group
therapy and educational services was in response to her son’s difficulty participating in groups.

Mothers also discussed sources of parent support since receiving the diagnosis for their
child. Two mothers stated that having a friend with a child with ASD provided a support network
and source of information. The other mother described accessing support from family members,
stating, “They’re interested in learning more which is helpful.” For this mother, seeing a
counsellor and having her “own person to talk to” was helpful, as well as assistance and
understanding from colleagues. The Facebook parent group was helpful for obtaining advice,
sharing and listening to stories, and forming friendships with other mothers they could relate to.

**Subtheme 3.2: What’s needed and challenges.** Mothers discussed difficulties and
insufficiencies they had experienced with their intervention team and with seeking support. One
mother had not experienced adequate help for her child or herself. She explained,
We’re missing the behaviour intervention aspect and we’re missing a real consultant who’s supportive of us and who is a part of our team...then respite is the other thing we’ve been [looking into] ...I feel like there could be more in the way of support.

This mother went on to describe the need for a consultant who is competent, supportive, and collaborative. A lack of support from family members put mothers in a position in which they had to defend her child, reinforcing that the label does not mean this is the end of the child’s life but that it’s just a word, and that their apologies are not helpful. For some mothers, being in a remote location limited the quality and quantity of treatment options for their child. While mothers indicated a desire for an in-person parent support group, distance and scheduling conflicts were indicated as barriers to pursuing that form of support. A mother also stated that finding a babysitter who could manage her child’s behaviour challenges made respite and mother-specific support almost impossible.

Figure 3.
Mother Thematic Map for Phase 3
Table 4.
Summary of Mother Perspectives: Phases, Themes, and Subthemes

<table>
<thead>
<tr>
<th>Phase</th>
<th>Theme/Subthemes</th>
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<tbody>
<tr>
<td>Before the Assessment</td>
<td><strong>Something’s Not Right: Is it me? Is it a phase?</strong></td>
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<td></td>
<td>Suspicions: Is it autism?</td>
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<tr>
<td></td>
<td>Isolation: Can’t go anywhere</td>
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<tr>
<td></td>
<td>Response by Others: No way or I think you’re right</td>
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<td></td>
<td>Agreeing with concerns</td>
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<td></td>
<td>Dismissal of concerns</td>
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<td></td>
<td>Waiting: Unable to get therapy started</td>
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<td></td>
<td><em>Already know it is ASD</em></td>
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<td></td>
<td><em>Wait-and-see</em></td>
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<td></td>
<td><em>Reflections</em></td>
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<tr>
<td>During the Assessment</td>
<td><strong>Getting the Diagnosis: Validating yet evoking worry</strong></td>
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<td></td>
<td>Reaction</td>
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<td>Meaning</td>
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<td><strong>Different Beliefs Than Spouse: Can’t deny the challenges</strong></td>
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<td>Certainty or denial</td>
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<td>Contention</td>
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<td>Delayed acceptance</td>
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<td><strong>What the Clinician Did and Said: Efficient and personable</strong></td>
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<td></td>
<td>Checking-in</td>
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<td>Clear and factual</td>
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<td><strong>Support Received: Helpful but not enough</strong></td>
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<tr>
<td>Moving Forward</td>
<td><strong>Readiness to Set-up Treatment: Let’s get started or feeling numb</strong></td>
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<td>Just needed diagnosis</td>
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<td></td>
<td><strong>Hopes and Fears: Being accepted and achieving milestones</strong></td>
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<td></td>
<td><strong>Support: Availability and accessibility</strong></td>
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<td></td>
<td>What’s available</td>
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<td>What’s needed and challenges</td>
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'See Appendix J for table of mother themes with sample quotes

**Perspectives of Clinicians**

Clinicians shared rich and detailed descriptions of their thoughts and experiences related to working with parents during the assessment process for ASD. They described perceptions of parents as they entered into the assessment process and when they were presented with the diagnosis. Strategies and approaches that they, as clinicians, used to inform, support, and guide
parents effectively were also discussed. Approximately 40 initial themes were identified from the clinician interviews. This was narrowed to fourteen themes and categorized according to the phase in the assessment process. Three to five themes were identified for each phase. These emergent themes are discussed below with descriptions of themes and supporting text quotes to reveal the patterned responses and meaning of participants. See Table 5 for a summary of phases, themes, and subthemes from the clinician data.

**Phase 1: Training and Experience**

Clinicians discussed the training and experiences they had working with children with ASD and their families, as well as conducting assessments for this population. This revealed the needs and interests that led them to this specialty area of practice and setting in which they worked. Clinicians described their academic and practical experiences through three themes, which are each discussed below. See Figure 4 for a visual organization of themes in this phase.

**Theme 1. Previous positions: Revealing need and interest.** Clinicians described positions they assumed before becoming a registered psychologist conducting ASD assessments. These included special education teacher, school psychologist, and behaviour therapist. This was typically their first experience working with children with ASD and their families, and evoked an interest in this population. The increasing prevalence of the disorder, struggles of these families to manage and understand their child’s behaviour, and need for diagnosticians became evident. One clinician described how her specialty in autism assessment developed, stating,

*I started working as a school psychologist…then I started private practice…a lot of our referrals are for autism assessment or treatment or intervention so it became apparent there was a lot of need for that.*
Theme 2. Education: Learning procedures rather than clinical skills. Clinicians described the various learning experiences related to ASD that they obtained in their undergraduate and graduate education. Varying degrees of focus were placed on ASD specifically in clinicians’ training, depending on whether their supervisor specialized in the disorder or not and whether practical experiences exposed them to this population to a greater or lesser extent. One clinician stated that his doctorate research on children with disabilities and their families got him interested in and introduced him to that area, while another identified coursework in graduate school and being his main source of learning about ASD and tools for assessing it. Another clinician had very intense training during her studies as a result of having professors whose speciality was ASD.

Clinicians described the greater emphasis in their graduate-level training on learning procedures related to psychological assessments and interventions as opposed to clinical skills such as addressing stressors parents are experiencing or communicating the diagnosis in a sensitive and clear manner. As one clinician stated, “We don’t get a ton of training in how to present feedback…it’s important…I mean, we were observed giving feedback but not a whole lot of real direct instruction and modelling in that.” It was believed to come down to a lack of time and the priority of learning administration procedures so as to conduct reliable and valid assessments. This was reflected by one clinician saying, “The emphasis is a bit more on the content, than it is on the process, of administering it…at the end of the day, you need to do the coding, so that’s what the training tends to focus on.” Overall, clinicians felt that the way in which an ASD assessment is conducted and the sensitivity with which they interact with these children and their parents is a clinical skill developed over time and with experience.
Theme 3. Perceptions of ASD families: Reacting rather than causing. Clinicians described the experience of working with families of children with ASD, and how they differ from other children with disabilities and their families. The training and practical experiences that clinicians were exposed to appeared to have contributed to the cultivation of these perceptions. One clinician explained the different orientation he took with families of a child with ASD after having spent a significant proportion of his graduate training working with families of children with conduct disorder. He stated, “A lot of times kids with conduct problems, the families are a part of their reason for that conduct issue…you’re often working on the family to help the child.” It became evident that clinicians developed a different perspective of families with a child being assessed for ASD, believing that it is not pathology or problems in the family that they are looking for. This shift in perception was indicated by a clinician’s statement that, “The parents are sort of collaborating in the process with me, of helping the kid develop a healthy sense of who they are.”

Figure 4.
Clinician Thematic Map for Phase 1
Phase 2: Before the Assessment

Clinicians described the events and circumstances that led parents to their office for an ASD assessment. Based on their experiences working with this population of parents, clinicians expressed a variety of concerns parents wanted addressed, what they were hoping to get out of the assessment, and where their head was at with regards to ASD. Clinician experiences fell into four themes and two subthemes, each described below. See Figure 5 for a visual organization of themes in this phase.

Theme 1. Referral concerns: Quirky or something else? Clinicians described the issues that parents presented when seeking an assessment for their child. Most concerns were related to behaviours consistent with the diagnostic areas for ASD, including difficulties socializing and communicating with others, and repetitive or restricted tendencies. Having read about ASD characteristics online, parents were described as often using scripted language from websites to describe their child’s difficulties. Clinicians also reported that parents have realized their child’s challenges are not just a phase. This was indicated by a clinician saying, “Parents will say things like, ‘They said it’d get better…he’d grow out of it’…and it’s just getting worse. He still doesn’t have any friends, and now he’s acting out.”

Clinicians also described parents seeking an assessment to tease apart their child’s constellation of difficulties so as to determine the main issue and any warranted diagnosis. They were faced with a lot of confused parents, desperately seeking answers as to how their reported concerns map onto their child’s profile and diagnostic criteria.

There’s some attention problems, there’s some repetitive behaviours. Is it ASD? Is it tics? Is it just stereotypic behaviour? Difficulties with social, communication, reciprocity... intellectually gifted. Is it something related to that? Are they just a little quirky?
Theme 2. Reasons for seeking an assessment: Answers and help. Clinicians described various reasons for parents making the effort to pursue an assessment for ASD for their child, and in some cases, to get a diagnosis. It became evident through clinician descriptions of their interactions with parents regarding what brought them to the assessment that they knew what ASD was and wanted the diagnosis so that they could get funding for intervention services.

Subtheme 1: Support. Clinicians described access to services as a main reason parents were attempting to obtain an assessment for ASD, since in BC the Ministry of Children and Family Development only provides funding for services once a diagnosis of ASD has been given. Clinicians working in private practice settings reported that parents had expressed a desire to get the diagnosis and begin therapy quicker as opposed to putting themselves on the waitlist for a government-funded assessment. Parents also reportedly sought support in the form of general parenting strategies suggestions from the psychologist as well as their opinion on which treatment options and resources to pursue for themselves and their child.

Subtheme 2: Second opinion. The clinicians conducting ASD assessments in private practices primarily saw school-aged children and many had been previously assessed through a government-funded assessment but no diagnosis of ASD was given. Parents came to them indicating that there are still concerns and they are still wondering what was going on with their child, many believing that it is ASD. Clinicians reported often agreeing that significant red flags are present and questioning the prior diagnosis or lack thereof.

We get a fair number second opinion requests where the family has gone in and seen some other professionals around an ASD diagnosis and been told no and want a second opinion. So they’re not often happy about that process if they believe their child truly does have ASD.
Theme 3. Who prompted the referral: Concerns become a reality. Clinicians reported that few parents self-refer, one indicating that approximately five percent make the call to the clinic themselves. The medical community was thought to be the primary referring group, given that the standard in BC is for a pediatrician to conduct the primary investigation and make a referral for further assessment. Friends, family members, and teachers were also reported to commonly bring the need for an assessment to the attention of parents. One Clinician stated that,

Some families come because they’ve been referred by a friend who has a child on the autism spectrum. And their friend says to them, “You know, your child has a few of these mannerisms and things that my guy did when he was that age and maybe you should go get an assessment.”

Clinicians indicated that professionals, including medical doctors and teachers, are more “up to speed” on signs for ASD and are thus more readily raising concerns to parents and suggesting an assessment be sought. This was indicated by a clinician who thought that, “as people become a little bit more and more aware of the symptoms on the higher end of the spectrum, they continue to ask questions.” The public’s increased awareness of the red flags of ASD and the use of screening measures was thought to help begin the process more efficiently, lessening the likelihood of going with a wait-and-see approach.

Theme 4. Suspicions of ASD: Research plants the seed. One clinician compared the awareness parents had of ASD at the early stages of his career to now. It was perceived that parents have gone from beginning the assessment with little to no suspicion of ASD specifically, to having done a lot of research on ASD and a strong inkling that their child’s profile maps onto the disorder criteria. The clinician indicated this has created shifts in psychologists’ role since they are no longer becoming concerned about ASD before parents and thus having to take great precaution in how to gather information and broach the subject sensitively. One psychologist
warned that easy access to information on the Internet sometimes contributes to inaccurate perceptions, jumping to conclusions, or the formation of biases. Thus, finding out what parents know about autism before the assessment begins is important to address preconceived ideas and find out the extent to which suspicions that their child has autism have been formed.

Clinicians stated that nowadays, parents approach the assessment having been told that ASD will be considered or even requested that ASD be checked-out. This was revealed through the statement that, “Parents are coming here going, ‘Listen, I want you to turn over every stone about this autism thing because I really think it is and the teacher really thinks it is.’” One clinician indicated that it is rare that a referral is made where the parents don’t have a clue that the psychologist will be considering autism. However, one clinician felt that, “Some parents are thinking it’s autism but they’re not coming right out and saying it.”

**Figure 5.**
*Clinician Thematic Map for Phase 2*
**Phase 3: During the Assessment**

Clinicians described the approach they took in carrying out the assessment, from the intake meeting to the meeting in which results were presented. Based on their experience working with parents as they assess the child for ASD, clinicians described their role in collecting information, addressing parents’ concerns and difficulties, and guiding parents through the steps for following through with recommendations for support. Clinician experiences and perceptions fell into five themes and six subthemes, each described below. See Figure 6 for a visual organization of themes in this phase.

**Theme 1. How families are presenting: Varied preparedness.** Clinicians described a wide variety of emotions that parents exhibited at the beginning of an ASD assessment. While some parents were stressed, confused, and tearful, others had done a lot of emotional groundwork and were confident in knowing what was going on for their child and their role was as the caregiver. This was thought to partly be due to the age of the child and prior experiences with assessment or treatment.

**Subtheme 1.1: Done the emotional groundwork.** Clinicians described parents who had already coped with the idea of their child having ASD and what that would mean for the child, parent, and family. These parents reportedly had built their knowledge base of the disorder and options, and knew what to expect in the assessment process. One clinician described these families as not necessarily at their “wit’s end” but rather as having accessed some help such as parent training or attempted to implement social skills strategies with their child.

*Families are coming to us pretty well prepared for the process. You know, they more often than not know what we’re looking for. They’ve got information on what autism looks like and what the concerns are and what kind of help is available should the child get a diagnosis and so on.*
Subtheme 1.2: Hard time dealing with pressures. Clinicians described a group of parents who, at the beginning of the assessment, struggled to make sense of what is going on for their child and how to best support them. One clinician perceived high levels of stress and depression to potentially result from raising a child with a disability and its isolating nature. Parents had also described frustration from ongoing challenges with their child not fitting in and not knowing why, as well as feeling they may have missed something. Several clinicians reported that parents expressed feelings of shame and guilt, that their parenting caused this atypical behaviour, and that they could have done more to optimize their child’s functioning.

[Has] been a struggle for quite a while and they might have had other parents and extended family feeling like that child is just badly behaved and you haven’t used well-developed parenting skills...Self-blame, guilt so yeah for sure I think families come in with pretty complex emotions... uncertainty and fear because ASD is out there and there’s a lot of fear associated with it.

Theme 2. Informing about the process: Steps and bringing up ASD. Clinicians reported that, in their experience, parents come into the assessment worried that you’re going to make a decision based on one visit with their child. As one psychologist explained, psychoeducation around the diagnostic process is important, explaining to parents, “we’re going to look at these various pieces of information from multiple sources across multiple types of assessment tools and we’re looking for a pattern.” Another clinician said that he found it helpful to ask parents in the first meeting if anyone had ever mentioned autism to them, stating to parents that some of the things he is seeing remind him of that. It was also believed to be important to let parents know that you are not going in with a narrow focus, searching only for ASD, but rather that a differential diagnostic assessment will take place with suggestions for support provided regardless of the outcome. This was reported to reliever parents, knowing they would be helped
even if their child does not receive the funding attached with an ASD diagnosis. Getting an idea of parents’ concerns and goals for the assessment was reported to help frame the clinicians’ response to the parent throughout the assessment. Clinicians also found it important to explain the kinds of things that would be done in the assessment, including the interview, observation, standardized testing, and completion of questionnaires.

Theme 3. Supporting parents: Concerns and strategies. Most clinicians described general methods of providing guidance to parents as they progress through the assessment, although one indicated that she attempts to keep the diagnostic process separate from the provision of support. Another clinician stated that supporting parents “is a little bit tricky when you’re in the middle of an assessment. You know, you want to know exactly what’s going on with that kid…and until you do, it’s hard to give parenting tips.” This clinician had also worked in a hospital setting doing ASD assessments and reflected, “It’s a circus…so it’s hard to do a good job of [supporting parents] when you’re in that kind of environment.” Various strategies were reported across clinicians with regards to addressing specific behavioural concerns or the emotional state of parents. These include digging for and exploring stressors for parents, providing emotional support in response, and general parenting strategies to address their child’s behavioural challenges. These practices are reflected in the following quotes:

*Identifying concerns when they come up. So parents won’t always say to you, “I’m feeling stressed out” or “I’m really not happy” but it...you know...eventually, if we do enough talking, we can kind of get around to that that’s, you know, what’s going on for some parents and then it’s kind of helping them find their own happiness.*

*It’s more just that emotional support. Doing that kind of clinical work while you’re in the room with them and just basically giving them the sense that you understand what they’re talking about...There’s a lot of relief that comes from that. Trying to provide that emotional support.*
Theme 4. Communicating results: Confirming but still a big deal. Clinicians discussed the way they approached the feedback meeting with the parents to discuss results of the assessment, any warranted diagnosis, and recommendations for support. All clinicians reported that while parents they see are often expecting and ready to receive an ASD diagnosis for their child, it is still a big deal and met with a wide range of questions and emotions. These perceptions seemed to have important implications for the way in which clinicians presented the assessment results to parents.

Subtheme 4.1: Strategies used. The clinicians developed particular strategies for sharing results of an ASD assessment with parents. Reviewing the process for the assessment was thought to be important, with one clinician stating, “I think that sets the stage for kind of trust that, ‘Oh right, we’re doing a comprehensive assessment. This wasn’t just a one-off meeting with my child.’” Another strategy was to use examples of what the child did or the parent stated and how each links to the ASD criteria with the hope that it is easily understood how the clinician came up with the diagnosis. Another aim was to receive confirmation from the parent that the results being described fit with the child they know.

Subtheme 4.2: Order of presenting results and diagnosis. There was some difference between clinicians’ views regarding whether the diagnosis should be communicated before or after symptoms are laid out. Two clinicians indicated that, particularly if parents came in thinking it was autism, cutting to the chase by indicating they meet criteria at the beginning of the meeting is most effective. This was thought to be effective in their experience because parents are “sometimes sitting there going, ugh get to the point, get to the bottom of it.”
Other clinicians reported that they have found that planting seeds by describing what they saw in the different diagnostic areas for ASD helps ease parents into it before saying that there is strong evidence the child has autism. One clinician added that if you give the diagnosis right away, the parent could get fixated on the diagnosis and have difficulty listening to the results.

**Subtheme 4.3: Considering audience.** Clinicians described ways in which their communication of results is driven by where they perceive parents to be at with receiving the information. As one participant stated,

*You need to be thinking about, how is this person receiving the message? Kind of reading the feedback because if I’ve got people looking at me kind of like tilting their head then you have to slow it down a bit, go back through. “Is there something I said that didn’t quite make sense?” or “Would you like me to rephrase that?”*

Other clinicians found that some parents were not ready to hear the results or are not in the right headspace to process the information. In these situations, sitting with them and expressing that it is difficult, meeting another time, or letting them talk through their emotions or resistance were reported to be helpful in communicating results.

**Subtheme 4.4: Instilling hope.** Clinicians described the importance of giving a sense of optimism to parents when communicating an ASD diagnosis, seeing as the repercussions for the child and family are often perceived as severe, long-lasting, and out of the parent’s control. One clinician stated that her hope is for parents to leave with the same unique child they walked in with, “that this doesn’t change who their child is, and the things they love about their child, and the fantastic things about their child.” Another method of instilling hope that a clinician described was communicating how well-researched ASD is, that with the knowledge of what treatments are effective, parents can be confident in the plan to move forward.
Theme 5. Reactions to the diagnosis: From relief to grief. Clinicians experienced a wide range of reactions from parents when the diagnosis of ASD is given during the feedback meeting. They reported having seen some parents in tears as a result of grieving the loss of normalcy in their child, while others were described as “fine and appreciative and accepting.” This was indicated through the following quote:

*I wouldn’t say [parents are] shocked. I would say, for most of them, it’s confirming because they have been on a long journey...by the time they get to me, this is not their first inkling that their child has autism.*

Almost all clinicians identified relief as the primary reaction of parents, given their already adjusted mindset from having researched the disorder and believing their child exhibits symptoms. As one clinician stated, “They’ve already maybe gone through a lot of the emotional ups and down of knowing something’s different, and certainly confirming what that is I think is probably helpful for them.” Clinicians felt that finally knowing what is going on for their child causes many parents to shift quickly to, ‘So now what?’ ‘What do we do?’

Clinicians also discussed those parents who begin to process what the diagnosis means for their child and family only once the diagnosis is received. As one stated, “They’re having to rotate on their axis and brace a whole new way of looking at their child...there’s a lot of emotional work that occurs in revamping their whole understanding and their life path.” For parents not expecting the diagnosis, the psychologist was thought to become part of that restructuring process and working through bereavement and sorrow.

Other reactions that clinicians reported that the parents expressed included worries, doubts, and confusion. They reported that parents will get in operation mode as opposed to reacting emotionally, wanting to know what needs to be done now to help their child. A clinician
indicated, “Most of parents’ worries are about what will happen to my child? Will they grow up? Will they be okay?” Her response was to guide parents to not be unrealistic but to have expectations and goals for their child down the road. When parents expressed hesitancies and doubts about how the diagnosis was determined, clinicians reported that describing the process and tools used has helped to demystify how evidence for ASD was gathered. A clinician reported that, “Some will ask me, ‘How come we got a diagnosis here but not there?’ And I just shake my head, ‘I don’t know. It’s a different process…so it looks different when we put it together.’” Finding out concerns and where any resistance may be stemming from were indicated as important components of the feedback meeting.

**Figure 6.**

*Clinician Thematic Map for Phase 3*
Phase 4: Moving Forward

Clinicians revealed their ideas and experiences pertaining to support and guidance offered to parents once the diagnosis was communicated and the meeting transitions to focusing on “Now what?” A variety of strategies were indicated, with perceptions of this phase falling into three themes, which are each discussed below. See Figure 7 for a visual organization of themes in this phase.

Theme 1. Guiding through resources: Practical rather than emotional support. In the feedback meeting in which the assessment results and any warranted diagnoses are communicated, clinicians also indicated that recommendations for supporting the child and parents are discussed. As one psychologist described, “My goal is to get to the bottom line with parents in feedback because that’s what they want. So [diagnosis] may take five minutes and then the rest of the session is what do we do?”

It became apparent that clinicians perceived the provision of tools in the form of information, access to funding, and treatment options to be what parents find the most useful and important as compared to support in addressing emotional reactions to the diagnosis. Clinicians stated that their role in guiding parents as they prepared to move forward with the diagnosis was to provide forms and contact information to access funding, providing pamphlets and information booklets on ASD and services, and connecting parents to consultants. Some clinicians indicated that they offer their own services in the form of follow-up meetings to further discuss results and services or providing intervention to child and the family. It was also stated that feedback from parents has revealed the value of guiding parents to opportunities to connect with other parents of children with ASD to explore similar experiences and feel less isolated.
Theme 2. Parent readiness: **Time to digest or ready to go.** Clinicians described a range of parent preparedness to discuss and follow-up with the recommendations for supporting their child and themselves as the caregiver. In their experience, some parents are immobilized once the diagnosis and resource information are presented. In one clinician’s opinion, these parents are going through the grieving process, in denial, or struggling to accept the diagnosis and its meaning. This was reported to limit parents’ readiness to discuss treatment options in the feedback meeting, rather needing the clinician to sit with them, listen and empathize, or provide further explanation. Clinicians described another set of parents they had worked with who are at first overwhelmed with the results and steps they need to go through to seek services, not yet ready to explore treatment options in the feedback meeting. However, the prospect of receiving funding quickly motivates them to get the process started, and then they are often back in touch with the psychologist to discuss services. The other set of parents described were those who were expecting the diagnosis, had already researched treatment options, and were ready to run with the diagnosis and report to access resources. Clinicians viewed these parents as not needing support in the feedback meeting or afterwards to unpack the meaning of the diagnosis or the emotions they were experiencing in response but are rather focused, clear-minded, and determined about what to do once they leave the clinician’s office.

Theme 3. **Responding to parents: Stepping back or forging ahead.** Clinicians described the importance of adjusting their approach to the feedback meeting with regards to how they explain the findings, diagnosis, and next steps based on the reaction of parents. As one clinician stated, “Being able to adjust how I’m speaking to them depending on whether they’re in a whole lot of denial, whether they’re completely on board, or whether they’re here to just seek some funding.”
Others have found that stepping back from the label of ASD and talking to parents about the concerns they have in relation to their unique child is helpful, or to explain to parents how ASD behaviours are manifesting in their day-to-day lives so as to reframe “misbehaviour” as behaviour their child is not doing purposefully. Another way clinicians reported responding to how parents were presenting during the feedback was finding out their strengths and where they are struggling. This was to identify supports to put in place so that parents are most likely to succeed in putting together the “intervention puzzle.” Finally, clinicians found that trusting parents to make the best decisions for their child by putting them in the driver’s seat was a way to respond to the needs and challenges of parents receiving an ASD diagnosis using a strength-based model.

**Figure 7.**
*Clinician Thematic Map for Phase 4*
Table 5.
*Summary of Clinician Perspectives: Phases, Themes, and Subthemes*

<table>
<thead>
<tr>
<th>Phase</th>
<th>Theme/Subtheme</th>
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<tbody>
<tr>
<td>Training &amp; Experience</td>
<td>Previous Positions: Revealing need and interest</td>
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<tr>
<td></td>
<td>Education: Learning procedures rather than clinical skills</td>
</tr>
<tr>
<td></td>
<td>Perceptions of ASD Families: Reacting rather than causing</td>
</tr>
<tr>
<td>Before the Assessment</td>
<td>Referral Concerns: Quirky or something else?</td>
</tr>
<tr>
<td></td>
<td>Reasons for Seeking: Answers and help</td>
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<td></td>
<td><em>Way to get support</em></td>
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<td></td>
<td><em>Second opinion</em></td>
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<tr>
<td></td>
<td>Who Prompted the Referral: Concerns become a reality</td>
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<tr>
<td></td>
<td>Suspicions of ASD: Research planted the seed</td>
</tr>
<tr>
<td>During the Assessment</td>
<td>How Families Are Presenting: Varied preparedness</td>
</tr>
<tr>
<td></td>
<td><em>Done the emotional groundwork</em></td>
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<tr>
<td></td>
<td><em>Hard time dealing with pressures</em></td>
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<tr>
<td></td>
<td>Informing About the Process: Steps and bringing up ASD</td>
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<tr>
<td></td>
<td>Supporting Parents: Concerns and strategies</td>
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<td></td>
<td>Communicating Results: Confirming but still a big deal</td>
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<td></td>
<td><em>Strategies used</em></td>
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<td></td>
<td><em>Order of presenting results and diagnosis</em></td>
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<td></td>
<td><em>Considering audience</em></td>
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<td></td>
<td><em>Instilling hope</em></td>
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<td></td>
<td>Reactions to the Diagnosis: From relief to grief</td>
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<tr>
<td>Moving Forward</td>
<td>Guiding Through Resources: Practical rather than emotional support</td>
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<tr>
<td></td>
<td>Parent Readiness: Time to digest or ready to go</td>
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<td></td>
<td>Responding to Parents: Stepping back or forging ahead</td>
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1See Appendix K for table of clinician themes with sample quote

**Cross-Group Perspectives**

Given the close communication and bidirectional influence of parents and clinicians in the ASD assessment process, the researcher looked across the groups’ perceptions of each other and what it is like to participate in this type of psychological assessment. Originally, the researcher planned to consider the consistencies and discrepancies between services clinicians purported to provide in the ASD assessment process and the needs or desires mothers reported to have as they underwent the assessment for their child. Through the data analysis process, it
became evident that participants focused more on the strengths and challenges that they and the other group experienced, as opposed to the services and practices provided or that were needed. This section aims to consider the findings described previously together by describing the consistencies and discrepancies between mothers’ and clinicians’ perceptions of strengths and challenges in the assessment process for ASD. See Table 6 for a summary of these findings.

**Perspectives of parent strengths.** Mothers and clinicians both indicated that parents’ breadth and depth of knowledge about their child facilitated the collection of information in the interview portion of the assessment. As one clinician stated, “As a parent, as a caregiver, a common thing they have is that they usually have a tendency to know their child the best. They’ve worked with their child this long.” Mothers indicated that knowledge about their child contributed to having strong beliefs about their child’s difficulties, whether the testing was an accurate representation of their child, and what form of treatment would best meet their child’s needs. As one mother explained, her “very strong feelings” about her child led her to trust her gut and motivated her to persist in seeking the assessment and treatment the child needed, even when faced with conflicting or mixed messages. Mothers also reported that taking initiative, by speaking to professionals and other parents to gather information, helped enhance their awareness and make smart decisions. This perception of parents as powerful advocates for their child was communicated by clinicians who stated that their “keen gut feeling” that something is going on for their child, and about what they needed, drove their determination to seek answers.

Another parent strength raised by both groups was parents’ knowledge of ASD as a result of researching the disorder through sources such as the Internet and books. Mothers reported being motivated to resolve their confusion by determining if what they were seeing was typical
or in line with ASD (for example, by completing online questionnaires). Some parents indicated that starting their research before the assessment prompted changes in their perceptions of their child and meaning attributed to the diagnosis and caregiver role, which helped with the preparedness and acceptance of the diagnosis. Clinicians perceived parents’ prior research as an indication of being highly organized, determined, and empowered when it came to understanding and helping their child.

Other strengths parents believed they demonstrated in the assessment process included being calm, which allowed them to process information and take action as opposed to getting stuck on negative consequences and their feelings. Also, being organized was stated as an attribute that made navigating the assessment and follow-up treatment provision easier. For example, one parent described sitting down and figuring out what form of services her child needed the most. Others took a systematic approach in listing all the steps they needed to complete to set up services, such as applying for funding and putting a team together. Clinicians also raised the point that the parents they have worked with exhibited incredible resilience and resourcefulness. One stated that, “Whether it’s been successful or not, [parents] have been doing things to try and adapt their environment and themselves to their child.” It was reported that even though many of these parents had been beat down, faced with barriers to services and challenges with caring for their child, they brought a lot of positive perspectives to the assessment process and remained empowered to do everything they can to help their child.

**Perspectives of parent challenges.** Both participant groups described the confusing and stressful journey of not knowing why the child was behaving that way, seeking out answers through an assessment, and setting up a treatment plan to help the child. Several parents
indicated that having their concerns dismissed by health professionals, family members, or friends was frustrating since they knew something was up. One parent interpreted this as a lack of belief in her “mother’s instinct,” which made her feel like she was “crazy” and had nowhere else to turn. She stated,

_I was talking to [the Occupational Therapist and Speech Language Pathologist] about what I was researching and my concerns and both ladies brushed it off and said, “You don’t have anything to worry about. I work with autistic children all the time and your child doesn’t have autism”…that was extremely frustrating to hear._

Clinicians had seen several parents whose concerns were dismissed in their first psychological assessment for their child, being told that an ASD diagnosis is not warranted, yet the child and parents continued to experience challenges and suspicions of autism remained. This was demonstrated by a parent stating, “You want to be able to support those families who are struggling. You know, certain parents can get depressed going through this process you know three times over the course of five years or more.”

Thus, clinicians perceived parents as struggling with not knowing what was going on and with the dissonance of believing it is autism yet being told it is not. Watching their child struggle to navigate the social world was even more challenging than coming to terms with the meaning of an ASD diagnosis. These challenges often evoked mental health and marriage problems in parents they see. As one clinician explained,

_Most parents have stress but parents of kids on the spectrum who don’t have the answers yet are still dealing from that, so have a higher stress level. And, you know, some parents get outright depressed, marriages break up…that’s not necessarily part of the assessment process, it’s part of living in that world or having a child with a disability and how stressful it is on your marriage. Hard on your own mental health. Hard on the marriage._

Parents and clinicians spoke to the daunting and time-consuming task that parents are faced with to seek out, select, participate in, and manage a team of professionals providing
services for their child. They perceived the challenge as particularly pronounced when considering the additional tasks of caring for the needs of their child and family, processing and adjusting to the diagnosis, and tending to their own self-care. This is evident through a clinician’s statement that, “It’s a lot of responsibility for the families. You know, you not only become a case manager, you become an employer, scheduler, bookkeeper.” As well as by a parent who reported,

After [the diagnosis] it was the daunting process of applying for funding, putting together a team...so now that you’ve actually got the label, you’ve got a lot to do ahead in terms of planning...I felt really numb...I felt kind of bad and disorganized.

A challenge depicted by mothers was being overwhelmed by the information provided in the feedback meeting. While the resources were thought to be plentiful and thorough, parents were unsure how to proceed with the process of selecting and seeking out services. This was indicated through the following statement by a parent:

I just said: What now? What do I do? Where do I go from here? Who do I talk to? And they basically just gave me all this information...Binder, folder like that, stacked full of pamphlets, forms, everything...I was overwhelmed.

Consistent with parent perceptions, clinicians indicated that parents wanted and needed guidance pertaining to treatment options for their child, however indicated that going through the package of resources in the feedback meeting was overwhelming. Rather, it was believed to be most productive for parents to take the package home and go through the information a little bit at a time. To address the challenge of being confused with the options and stress of seeking services out, clinicians expressed that parents found it helpful to come back for a follow-up meeting to discuss options further once they had learned what these were.
Being overwhelmed also came from the information provided regarding the assessment results and diagnosis, with the complexity and emotional reaction. This reportedly led them to “freeze” in the feedback session while limiting their ability to process and generate questions. As a parent stated, “[The clinician] gave us an opportunity for questions. I think that we were—well, my husband definitely was overwhelmed. I don’t think he had any questions. I didn’t.”

However, parents indicated that they could email or meet again with the clinician to explore questions and concerns once they had time to digest the results. Also, just being given the opportunity to voice their thoughts and questions evoked a sense that they were not being rushed or “kicked out of the office”, which was appreciated.

**Perspectives of clinician strengths.** Both groups of participants brought attention to clinicians’ sensitivity to where the family is at in that moment, particularly as they conduct the feedback meeting. This was perceived by clinicians to facilitate parents’ expression of their emotions when receiving the diagnosis, and is a clinical skill acquired through experience. As one clinician described his attempt to “meet them where they’re at in receiving that diagnosis” and support them as they receive this difficulty news. Mothers thought it was important that their clinician picked up on when information was confusing or emotionally laden for them. Mothers communicated their perception that the clinician was personable and took the time to get to know the child and hear what the parent had to say. Feeling that the clinician did all she could to figure out what was going on was a big deal for mothers. As one mother stated,

*The psychologist had a] warm demeanour and was tuned in...I really felt like she saw who he was. So to us, that was really important. She described exactly the boy that we know, that she had seen...she said he was great, he has these strengths and these interests.*
This evoked a sense that they could trust the clinician in making the final decision, seeing as they had taken it upon themselves to learn as much about the child. Consistent with these findings, clinicians indicated that their ability to communicate the diagnosis clearly and confidently helps parents leave with clear direction as what to do next.

Clinicians believed that spending time instilling hope and reassuring parents about the sufficiency of treatment options and their child’s future was an important part of the feedback meeting. Mothers, on the other hand, tended to value the factual nature of the meeting. Going through the assessment process was felt to have prepared them for the diagnosis thereby dismissing the need to be babied or for sympathy to be offered by the clinician. Their focus was on hearing the scores, symptoms, diagnosis, and next steps. As one parent explained,

*Straightforward, to the point, these are our findings, this is what we feel the child needs...they gave me all the tools. I left having all the tools I needed to move forward with it. You know, now the journey begins.*

Clinicians in private practice indicated that having flexibility to take the time they needed to reach a certain level of certainty was a strength in their practice. Mothers reported being focused on getting the diagnosis as quickly as possible so that they could access services.

**Perspectives of clinician challenges.** Seeing as the mother participants had little insight into the job responsibilities of a psychologist and the challenging aspects of a clinicians’ role in conducting ASD assessments, only clinicians’ perceptions of difficulties they face as a diagnostician are discussed here. As one clinician described,

*Often the greatest challenge is that they also have a distinct bias...they will come with sort of some preconceived ideas whether their child is autistic or not. You have to really work with that part...if it’s not in line with the findings then that’s the challenging part.*
These preconceived ideas were believed to be a result of parents’ extensive research prior to beginning the assessment. Moving parents away from listing symptoms they had read online, and towards describing behaviours seen in their child, was indicated to be a challenge when interviewing parents. The misinterpretation of questions, or difficulty generating examples from when the child was much younger, were found to make it hard for clinicians to gather accurate and sufficient background information from parents about the child.

Given the heritable nature of ASD, these clinicians were often working with parents with ASD symptoms themselves. A clinician stated,

*If you think about genetics, a lot of the parents would have a few of those symptoms if not the whole spectrum so there’s a certain kind of demeanour that goes along with that. They’re pretty fact-focused and to the point. Sometimes pretty blunt about things and that’s got its drawbacks but you know if what I want is the facts, then that’s a strength.*

Fathers were most often the parent exhibiting these characteristics, focusing on practicality and sometimes having a hard time recognizing the abnormality in their child’s behaviour. This created a challenge for clinicians as they attempted to delve into what a diagnosis means while balancing the emotions or lack thereof of both parents. Clinicians also found that being faced with other mental health issues parents experience, including stress, anxiety, and depression, can sometimes make it hard to gather information about the child when also needing to address the parent’s difficulties and consider how they are influencing perceptions of the child’s functioning.

An additional challenge reported by clinicians included denial of a diagnosis of ASD. As one clinician stated,

*On a few occasions, parents being in a lot of denial about this being autism. That’s definitely a challenge. Denial about whether it fits the label of autism I think often comes from a place of feeling like this is the kind of thing they need to be ashamed of.*
To address this challenge, the clinician reported that sensitivity to baggage and previous experiences influencing current perceptions, and adjusting how you communicate depending on their acceptance level, are important factors. This denial appeared to often be when the diagnosis was not clear-cut and the parents were not convinced or prepared for a label of ASD when they came into the assessment. A clinician reported that, in these cases, she has found it important to convey having done due diligence and jumped through all the hoops to come up with an accurate conclusion that best meets the needs of the child.

Table 6. Summary of Strengths & Challenges as Perceived by Mothers and Clinicians

<table>
<thead>
<tr>
<th>Parent Strengths</th>
<th>Mother Perspectives</th>
<th>Clinician Perspectives</th>
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<tbody>
<tr>
<td></td>
<td>Strong feelings about child</td>
<td>Know child best/source of info</td>
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<tr>
<td></td>
<td>Research</td>
<td>Intuition/keen gut feeling</td>
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<tr>
<td></td>
<td>Being calm</td>
<td>Advocates</td>
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<td></td>
<td>Trusting gut and advocating for child</td>
<td>Motivation to research ASD</td>
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<td></td>
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<td>Positive, empowered, &amp; resilient</td>
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<td></td>
<td></td>
<td>Organized</td>
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<td></td>
<td></td>
<td>Motivation to get answers/help</td>
</tr>
<tr>
<td>Clinician Strengths</td>
<td>Pointing out strengths</td>
<td>Sensitive</td>
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<tr>
<td></td>
<td>Communicating they saw child</td>
<td>Attuned</td>
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<tr>
<td></td>
<td>Tuned into parent</td>
<td>Experience</td>
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<tr>
<td></td>
<td>Clear, factual, knowledgeable</td>
<td>Thoroughness &amp; Flexibility</td>
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<tr>
<td></td>
<td>Being available</td>
<td>Instilling hope &amp; reassurance</td>
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<tr>
<td>Parent Challenges</td>
<td>Concerns not validated</td>
<td>Mental health/marriage</td>
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<tr>
<td></td>
<td>Rushing</td>
<td>ASD not on parents’ radar</td>
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<td></td>
<td>Overwhelmed by information</td>
<td>Responsibility</td>
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<tr>
<td>Clinician Challenges</td>
<td>Parents’ preconceived ideas</td>
<td>Overloaded with options</td>
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1See Appendix L for perceptions of strengths and challenges with sample quotes.
Chapter 5: Discussion

The purpose of the current study was to better understand the experience of parents and clinicians as they progressed through the assessment process of a child with ASD. While originally the study was to focus on parents more broadly, the final sample of parents was only mothers living in two parent home contexts. This prompted a change in interpretation from parents in general to mothers specifically. Perceptions of strengths and challenges for clinicians and mothers were also explored across groups. Uncovering the perceptions of mothers and clinicians as to what worked well and not so well throughout the assessment process revealed best practices for supporting parents as they seek an assessment, receive the diagnosis, and attempt to implement recommendations. Semi-structured interviews were conducted with three mothers and five clinicians in Lower Mainland British Columbia. Transcripts were analyzed using a thematic analysis approach. Through review of the mother interview data, twelve themes emerged across three phases of the assessment process. Findings revealed their thoughts and experiences before, during, and after receiving the ASD diagnosis and its impact on their child, family, and their role as caregiver. Review of the clinician data revealed fourteen themes across four phases, illustrating perceptions of parents coming in for an assessment, the approach taken in gathering information and communicating the diagnosis, and strategies used for guiding parents through recommendations for support. Findings indicated that mothers were often convinced that their child was presenting with ASD symptomology long before the assessment began. The stress experienced appeared to result from barriers in seeking an assessment all the while watching their child suffer, as opposed to dissatisfaction with the assessment itself. Variations in perceptions of the balance between the delivery of facts and resources, and
provision of emotional support during the feedback meeting were revealed across and between mothers and clinicians. While some participants reported readiness to take the diagnosis and get going with setting up treatment, others reported a sense of being overwhelmed, needing time to digest the information and pursue a follow-up meeting to further discuss options further. In this chapter, the research findings are discussed in relation to previous literature on the topic. Limitations and strengths of the study are explored, as well as implications for parents and clinicians, and recommendations for future research.

**Findings in Relation to Previous Literature**

**Before the assessment.** For the mothers in this study, concerns and suspicions about their child began long before the assessment got underway. Similar to what was found in previous studies with parents of children diagnosed with ASD (Mulligan et al., 2012; Woodgate et al., 2008), initial suspicions were triggered by delayed onset of developmental milestones or differences in behaviour, language, and social functioning. The distressing thoughts and emotions that parents experienced in response to these suspicions, including confusion, helplessness, exhaustion, and self-blame were consistent with the mental health problems uncovered in related studies of parents’ experiences before their child received a diagnosis of ASD (Weiss, Cappadocia, MacMullin, Viecili, & Lunsky, 2012). This study added the insight of clinicians, who perceived parents as often being in a state of distress prior to beginning the assessment. This was thought to be a result of not knowing which of the many proposed problems or disorders their child is suffering from, unsuccessful attempts to help their child, or a strong belief that it is ASD despite this diagnosis being dismissed in prior assessments. Similar to previous studies, this study revealed that despite experiencing these challenges, mothers reported
“sticking to their gut feeling” and persevering to find answers and help their child. This study also indicated that clinicians have an awareness of the stress and motivation behind seeking an assessment, and points to the critical position clinicians are in to address the hardships of caring for a child with ASD symptomology before a diagnosis is officially made.

Consistent with parent reports in Mulligan et al.’s (2012) study, mothers in this study addressed their suspicions by dedicating time to learning about ASD. Parents appeared to be motivated by a strong belief that their child had ASD and eagerness to receive the diagnosis so they could receive funding for services. Clinicians indicated that, more and more, parents come in requesting that they look into autism as a result of noticing similarities between ASD symptoms read online and their child’s behaviour. This highlights the importance of clinicians recognizing parents’ attempts to learn more about ASD as both a mechanism for enhancing knowledge and preparation for a diagnosis, as well as a contributing factor to preconceived biases and beliefs about the reasons behind the child’s difficulties. Clinicians are also being faced with parents who have researched intervention services available for ASD, which may help to explain the frustration expressed by mothers of not being able to pursue services for their child until the diagnosis and funding are granted.

The finding that the mothers perceived that they were isolated before the assessment, specifically that no one understood, there was nowhere to turn to for help, and they had no choice but to stay home, was consistent with prior studies examining the experience of parents of children with ASD (Cashin, 2004; Dale et al., 2006; Mulligan et al., 2012; Woodgate et al., 2008). This indicates a need for initiatives to support parents when concerns are first raised and a referral is being pursued in order to reduce the likelihood of mental health problems in parents
and enhance their ability to address their child’s difficulties even if a diagnosis and funding have not yet been received. These support initiatives could include parenting strategies for outings in the community and information regarding free intervention programs for children with special needs. The dismissal of concerns by family members, friends, and professionals that mothers in this study reported appeared to augment their perceptions of an unsupportive system and diminished hope for their family regaining connectedness. This points to the need for helping parents going through an ASD assessment find a way to maintain a positive quality of life even when faced with uncertainties and challenges due to their child’s behavioural disturbances, judgement when out in public, and limited resources when a diagnosis has not yet been made.

The lengthy process that mothers in this study described with regards to seeking an assessment and obtaining an ASD diagnosis was consistent with prior studies (e.g., Abbott et al., 2013; Sikos & Kerns, 2007). This study revealed that the waiting involved in obtaining referrals to even get a referral for an ASD assessment followed by waiting for the assessment to begin was frustrating primarily because mothers were already convinced that the end result would be a diagnosis of ASD. Additionally, given enhanced public knowledge of the importance of early identification and intervention (Charman & Baird, 2002), mothers felt like they were doing all they could yet were still unable to begin the treatment for their child that had potential to lead to the improvements they so desperately wanted to see. This suggests a need to equip parents with tools to meet their child’s needs before accessing professional guidance, as well as to provide clear steps regarding the referral process and explain the thorough nature of an ASD assessment. Findings also highlight the impact of professionals’ dismissal of concerns on extended waiting periods and parent frustration. This highlights the importance of the widespread use of valid and
efficient screening tools for ASD symptoms in order to decipher the need for a full assessment in a time-efficient manner.

**During the assessment.** Despite attempts in British Columbia to implement consistent procedures and standards for the ASD assessment and diagnostic process, previous studies revealed that parents in BC continued to be dissatisfied and perceive the ASD assessment as stressful (Sikos & Kerns, 2008). This study revealed that pursuing a government-funded assessment (often done in one day) or a private assessment (often done over multiple days) both led to parent satisfaction with the clinician and the way the process was carried out. It appears as though clinicians conveying the purpose of the assessment, that ASD will be looked into, and that they have made a point of getting to know the parents and child, contributes to parents trusting the clinician while feeling understood and empowered. Thus, in accord with best practice guidance (National Autistic Society, 2003; NICE, 2011), building a positive parent-clinician relationship throughout the assessment process has the potential to enhance satisfaction as well as parent and child outcomes. Results of this study revealed that clinicians’ attempts to provide emotional support may be met with resistance if parents feel babied and pitied when they have already accepted the ASD label as the reason behind their child’s challenges and just want information and resources. In previous studies, parents have been found to experience a blunt delivery of results and diagnosis without exploring emotional reactions (Chamak, Bonniau, Oudaya, & Ehrenberg, 2011) while others reported feeling overloaded with information thereby prolonging the emotional impact of the diagnosis (Abbott et al., 2013). This study revealed that the opportunity to ask questions or request a follow-up meeting helped mothers feel in control and able to adapt at their own pace. Clinicians indicated that their provision of contact
information and offering to meet again reassured parents that they would not be alone and could come back when they were ready to further explore the diagnosis and treatment options.

The feedback meeting during an ASD assessment, in which results and diagnoses are communicated, has been established as an intense and overwhelming event for parents (Brogan & Knussen, 2003; Howlin & Moore, 1997; Mulligan et al., 2012; Solomon & Chung, 2012). Results of this study indicated that while mothers perceived receiving the diagnosis as a big deal, their reaction was primarily indicative of justification of their suspicions and efforts, and relief that they knew what was going on for their child and what to do to help. This was consistent with the mixed feelings that parents in Chamak et al.’s (2011) study experienced upon receiving a diagnosis of ASD for their child. Clinicians perceived the delivery of a diagnosis as either evoking confirmation or fear for parents. The range of reactions suggests a necessity for clinicians to gage parents’ preparedness and understanding so as to tailor the content of feedback sessions to the individuals involved. For example, determining whether to address bereavement and join in on the emotional groundwork involved in shifting perspectives, or to quickly move onto the provision of information and recommendations. This is an important consideration seeing as positive perceptions of, and adoptions to, the diagnosis can contribute to a reduction in frustration, isolation, conflicting messages, and self-blame that these parents often experience.

Moving Forward. In accord with findings of similar studies, absorbing and assimilating the assessment results as well as next steps for seeking funding and services has been found to often result in information overload for parents (Abbott et al., 2013; Mulligan et al., 2012). Clinicians in this study perceived parents as eager to move onto the “now what?” portion of the feedback meeting and indicated that parents may convey an understanding of the diagnosis and
readiness to move forward when in fact they need time to absorb and process the information, and ask questions. Findings of this study suggest that a follow-up meeting, once results have been digested, may help to ensure that parents are in the right headspace to learn about services available and how to go about setting them up. In accord with previous research (e.g., Brogan & Knussen, 2003), the overall aim is to achieve a balance between acknowledging parent concerns with warmth and responsiveness, and identifying supports in a clear and comprehensive manner. The challenge, according to clinician perceptions in this study, appears to be gaging and being sensitive to where parents are at with assimilating the diagnosis into the meaning they attribute to their child, family, and caregiver role to know what balance is needed to meet parents’ needs.

The mother participants did not believe adequate information was provided regarding community supports for them as parents, even though clinicians perceived this to be necessary given the demands on caregivers of children with ASD. This indicated that while sufficient information regarding resources is being provided to parents, there is a need for professional guidance on how to go about acting on the recommendations while simultaneously attempting to adapt their mental concept of their child and role as caregiver. As revealed by Mulligan et al. (2012) and in this study, parents considered the diagnosis to be a gateway to services, evoking hope for lessening symptoms. However, parents were often met with disappointment and frustration with the quality of resources as well as their limited availability and restrictions to eligibility, and lack of professional guidance (Siklos & Kerns, 2007). Clinicians in this study shed light on their attempt to provide a depth and breadth of information regarding community resources for children with ASD and their family, and opportunities to meet again to discuss the diagnosis and next steps. There appears to be a need to recognize strategies clinicians use in the
feedback meeting so as to reduce the likelihood that parents leave feeling numb and disorganized, in addition to providing opportunities for follow-up. Also, focusing on the equal provision of resources for child and parent is necessary to enhance parents’ ability to adapt, gain control, and be mentally, emotionally, and physically fit to meet their and their child’s needs.

**Implications for Parents**

Findings suggest that parents should be encouraged to trust their instinct when they sense that something is not right with their child. While others may attempt to provide reassurance that it is just a phase, it is important to go with this gut feeling and be an advocate by seeking answers. Mothers in this study took the perspective that if someone was not being supportive with their belief or decision, it was best not to listen to them but rather do what they thought their child and family needed. If a clinician says something like, “No, he’s just quirky. Let’s wait another year and see if anything changes,” stick to that instinct and push back or continue seeking help and answers through other means. Seeing as parents know their child the best, and early intervention is critical for ASD, there is a time sensitive period for following through with concerns and attempting to get the child assessed.

Parents should be encouraged to research ASD to learn about characteristics and begin thinking about how they relate to their child’s presenting problems. However, caution is warranted in getting caught up in the “scripted symptoms” and thinking only in terms of the diagnostic criteria they read online as opposed to their child’s unique behaviours. It may be helpful to talk to friends or family members who have a child with ASD to learn about their experiences and child’s characteristics. Connecting with others is not only a way to learn more, but also to reduce isolation by recognizing that there are others going through the experience.
while also finding activities that children with ASD and their parents can do together. Informing oneself through research, connecting with others, and addressing personal care needs are ways to get into a calm headspace to face the assessment process and parenting responsibilities.

Parents’ attempt to understand why their child is having difficulties can often evoke disagreements between spouses and differing beliefs as to whether or not they have a specific disorder. Findings from this study point to the potential benefit of spouses and family members researching ASD together and discussing how the symptoms they are reading map onto the behaviours their child is exhibiting. This can help to slowly move parents to be on the same page and become a team when seeking an assessment and support, as well as to provide consistent information and viewpoints to the clinician during the parent interview component.

Based on experiences that mothers in this study reported when going through an ASD assessment for their child, they may find it beneficial to prepare their child for the testing situation. This could be as simple as explaining to them that some of the activities may seem boring but they have to get through them and it is just important that they try their best. During the assessment, some parents might find it helpful to bring up issues that are evoking stress for them as a parent, or marital conflicts that have risen. Alternatively, parents could consider seeking their own support through a counsellor, friendships, or self-care. This is important to address, given its potential influence on a parent’s capacity to effectively meet the demanding needs of a child with ASD. This population of parents can get so caught up in advocating for and seeking help for their child that they neglect to address their own needs and challenges. Evident through mothers’ statements in this study, clinicians conducting ASD assessments can be great listeners, advice providers, and sources of information regarding resources for parents of children
with ASD. See Table 7 for a summary of tips and tricks revealed through results of this study that parents may find helpful as they prepare for and go through an ASD assessment.

**Implications for Clinicians**

The literature provides insights into guidelines for how clinicians should conduct ASD assessments based on perspectives of parents. However, minimal research has considered feedback from clinicians pertaining to what they find to work well and not so well in working with parents throughout the assessment process. The results of the present study revealed consistency between parent and clinician perspectives that opportunities to ask questions and for follow-up facilitate healthy emotional adjustment in parents and a sense of trust and confidence as they move forward with next steps. Clinicians additionally viewed this practice as a way for them to ensure that parents have understood the results and diagnosis, and that there are no doubts or denials in parents’ acceptance of the diagnosis.

Parent and clinician perspectives revealed through this study also point to the importance of clinicians being sensitive to where parents are at in anticipating or accepting ASD as the diagnosis warranted for their child. Exploring a parent’s hypotheses about what is going on with their child, information they have sought, and stressors they have experienced can help determine the best way to communicate with and support parents. Deciphering whether to step back and further explain how examples map onto criteria or to quickly moving onto next steps is important for clinicians to have confidence they are meeting the individual needs of parents. The ultimate goal is for parents to be adequately equipped to walk away from the clinician’s office and efficiently and effectively put supports in place for them and their child.
A collaborative and strength-based approach was revealed by clinicians to be effective for gathering adequate and relevant information from parents, and to enhance their self-efficacy as a caretaker of a child with special needs. Parents appreciated this approach, giving them the sense that they were valued and had some positives to draw upon. It appears as though a clear and factual presentation of results, with limited sympathy and emotion exploration, was most helpful for parents and perceived by clinicians as what parents desire. Recognizing that parents tend to have already come to terms with their child having ASD or feel numb and need time to digest their information before exploring the diagnosis and recommendations with the clinician.

The results of this study point to the potential utility of a tool for measuring parent satisfaction with the ASD assessment process and success in following through with recommendations. This could be a brief questionnaire given to parents shortly after their last meeting with the clinician, and could address what they found satisfactory and unsatisfactory with the assessment, parent stress levels before and after the diagnosis, comprehension and acceptance of the diagnosis, and positive and negative experiences with seeking support for them and their child. Additionally or alternatively, period check-ins with parents throughout the assessment and in follow-up could be conducted to determine what they think is working well and if the level and type of support being provided is meeting their needs. See Table 7 below for a summary of strategies that may enhance effective practice in conducting ASD assessments.

Implications for School Psychology Training

Graduate level training in school psychology is an important context in which skills needed to conduct assessments and formulate a diagnosis of ASD are taught. This includes the administration of intelligence tests, the Autism Diagnostic Observation Scale (ADOS) and the
Autism Diagnostic Interview (ADI), writing psychological assessment reports, and procedures for conducting feedback sessions with parents. Some doctoral level school psychologists conduct assessments for ASD in settings such as schools, hospitals, or private practice. Findings from this study reveal considerations for teaching skills to future clinicians that will translate into conducting comprehensive assessments while simultaneously building a trusting relationship with parents, thereby enhancing their level of satisfaction with the process. Through interviews with clinicians in this study, it became apparent that more focus is being put on the administration of measures as opposed to clinical skills. However, mothers indicated that they valued the clinician being attuned to them and their child. This points to the need for school psychology training to offer opportunities for students to practice and receive feedback on being sensitive to where parents are at. This includes being attuned to their suspicions of and reactions to the diagnosis, listening and responding to voiced concerns, communicating that they saw the child for who they were, and instilling hope while also being realistic.

This study also revealed the doubt that parents sometimes express about whether adequate information was obtained and opportunities to see the child were pursued to make a valid diagnosis. School psychology training has the unique ability to provide students with practice conducting assessments in school and clinical settings, using multiple measures, gathering information from various sources (e.g., teachers and Educational Assistants), and working in a multidisciplinary team. This puts school psychologists in a unique position, as they have access to the tools they need to conduct comprehensive assessments for ASD that will help to assure parents that the final results provide an accurate depiction of their child. Table 7 reveals clinical skills to address parent challenges that could be considered for training purposes.
Table 7.  
*Putting Findings into Practice*

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<tr>
<th>What Parents Found Challenging</th>
<th>What Parents Valued</th>
<th>Strategies Clinicians Found Effective</th>
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<tr>
<td>Disagreement with spouse</td>
<td>Researching ASD</td>
<td>Viewing the family as <em>reacting</em> rather than <em>causing</em></td>
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<tr>
<td>Concerns being recognized</td>
<td>Having concerns validated</td>
<td>Informing about the process, throwing ASD out there</td>
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<tr>
<td>Implementing recommendations</td>
<td>Online support groups</td>
<td>Asking about and exploring the challenges as a parent (e.g., stress, shame, guilt)</td>
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<tr>
<td>Accessing parent support</td>
<td>Clinician communicating they saw and understood child</td>
<td>Giving parenting strategies</td>
</tr>
<tr>
<td>Seeking intervention team</td>
<td>Clear and straightforward results using examples</td>
<td>Mapping results/examples onto criteria</td>
</tr>
<tr>
<td>Concern about child’s future</td>
<td>Opportunities to follow-up</td>
<td>Exploring reaction to diagnosis and empathizing</td>
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<tr>
<td></td>
<td>Parent support resources</td>
<td>Moving quickly onto tools, info, and resources</td>
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**Limitations and Strengths of the Present Study**

Through the present study, the experiences of mothers and clinicians in the assessment and diagnostic process for ASD were examined. Although results helped to better understand practices and techniques that work well and not so well when going through the assessment, the study does have some limitations that should be recognized. Firstly, the sample size was small, although it did have the expected number of participants outlined in the original research proposal and was consistent with related studies in the literature. Despite extensive recruitment efforts, it was challenging to find parents who were willing to share their story and clinicians who had time in their schedules to conduct the interviews. As addressed in Chapter 3, a small sample is not unusual in qualitative studies so as to allow for each participant’s experience to be explored in depth, and for detailed analysis to take place. Nonetheless, this was still a small sample even given the approach taken.
The lack of diversity in the sample was also a limitation. The study involved only clinicians and mothers who agreed to participate, meaning that they initiated their involvement. It is possible that parents who had a more positive assessment experience and clinicians who were confident in their skills and practices were more inclined to participate. As suggested by Heiman (2002), volunteer participants may exhibit unique qualities and more bias than those who did not elect to partake. Although attempts were made to recruit a diverse sample, in the end, snowball sampling was used. This led to heterogeneity in the final sample given the interrelationships and commonalities of individuals, which limited the potential for unbiased estimation and generalizability (Faugier & Sargeant, 1997). The clinician participants worked in private practice, with the exception of one who mostly worked in the school setting. It is possible that different referral concerns, flexibility in scheduling, primary age groups, and parent stress and suspicions of ASD are evident in private versus public assessment settings. Also, clinicians were all psychologists thereby narrowing the viewpoint by not considering the approach taken by other clinicians such as psychiatrists and paediatricians. Parent participants were all mothers in two-parent families. While mothers shared insight into their husband’s experience of the assessment, it is important to highlight that this was an indirect way of gathering perceptions of fathers. It is possible that obtaining the voice of the father through the mother contributed to biased and inaccurate portrayals of what the father experienced in reality. Given the study findings that higher divorce rates in families with a child with ASD (Hartley et al., 2005) and the benefit of added help from a second caregiver (Siller & Sigman, 2008), parent results of this study may have overestimated the level of functioning of families with a child with ASD.
Despite these limitations, the strengths of this study include its contribution to the literature on the ASD assessment and diagnostic process from the perspectives of both parents and clinicians. Revealing clinical skills and practices found to be effective in this process is important given the stress and complexity that has been found to encompass a parent’s experience of having their child assessed for and diagnosed with ASD. There has been limited research examining what clinicians purport to do to support parents, and what parents view as necessary and helpful before, during, and after the assessment. The findings of this study shed light on the variety of beliefs, feelings, and levels of motivation that parents have, as well as the variation in clinicians’ perspectives regarding parents, and approaches taken to assess the child and guide parents. This study helps to fill the gap in the literature while revealing suggestions for best practices to ameliorate the functioning of both parents and children with ASD.

Another strength of the current study was the researcher’s lack of affiliation with the private practice in which clinicians worked, or the hospitals in which parents sought their assessment. This reduced bias since the researcher had no prior knowledge pertaining to the standard practices used in these settings and thus no preconceived ideas were developed, no leading questions were asked, and the participants could be confident that their responses would no have negative repercussions. Additionally, the study used one-on-one interviews to allow for an in-depth exploration of experiences and thoughts pertaining to ASD assessments, as well as flexibility in content covered depending on the unique ideas being presented by the participant.

**Directions for Future Research**

To further enhance literature on the ASD assessment and diagnostic process, it would be beneficial to replicate the current study with groups of clinicians and parents each containing
participants from private settings (e.g., private practice) and public settings (e.g., schools, hospitals). This would facilitate a more in-depth comparison between the experiences and satisfaction of participants in these settings. The current study provided preliminary indications that factors such as cost, approach, referral concerns, and pace of the assessment as well as age of the child tend to differ in private versus government-funded contexts. Further examination would be important to confirm similarities and differences, and benefits and drawbacks between the two systems. It would also be beneficial for subsequent studies to include father participants in addition to mothers, as well as parents of one-parent households, to better understand any differences in their experiences. Including other clinicians conducting assessment for ASD, such as paediatricians and psychiatrists, would facilitate understanding of experiences and ideas regarding strategies, approaches, and timelines within a wider context of assessments for ASD.

Future studies could modify the order in which interviews are held so as to allow preliminary interviews to inform subsequent interviews. The current study conducted interviews with parents and clinicians simultaneously, but it would be interesting to first hold clinician interviews and use revealed strategies to inform parent interviews by inquiring about their response to what clinician are purporting to be doing. This approach would be most informative if parent participants were previous clients of clinician participants so as to understand whether strategies are as effective as clinicians perceive them to be. Also, holding interviews with parents and clinicians before, during, and after the assessment could help to differentiate experiences in each phase as opposed to having participants reflect on the whole process at the end. This could reduce the risk of parents’ experiences during and after the assessment biasing perceptions of what it was like before the assessment.
Since the diagnosis of a disability can impact families in a variety of ways (Seligman & Darling, 2007), measures of parent stress, family quality of life, and severity of child symptomology completed after the assessment and considered along with supports received for the parent and child. This could be important in identifying whether the support and guidance from the clinician during the assessment helped to set parents up for successful adaptation and healthy functioning post-assessment. Examining the quality and quantity of information provided to parents regarding resources (e.g., pamphlets, contact sheets) may also further reveal what is contributing to the success or frustration parents are experiencing in setting up supports for themselves and their child.

Conclusions

This study explored the thoughts, experiences, and needs regarding the assessment and diagnostic process for ASD from the perspectives of mothers and clinicians. Participants described the stressful nature of parenting a child with ASD, living with the uncertainty before a diagnosis is given, eagerness to obtain funding and seek treatment but having to wait for the diagnosis, strategies employed by clinicians to put parents at ease, and what it was like to seek support once the assessment was completed. The challenges of the assessment process, as well as strengths or what was found to be helpful, were fairly consistent across parent and clinician reports. Findings revealed recommendations for practice that can serve as guidelines for clinicians to address the concerns and needs of parents in a straightforward yet sensitive way. This study is in keeping with the importance of a positive parent-clinician relationship outlined in best practice guidelines (National Autistic Society, 2003) and literature on this topic (e.g., Abbott et al., 2013). Feeling heard, validated, supported, and adequately equipped with resources
for support can help parents better manage the distress and challenges they experience when a diagnosis of ASD is made, while optimizing the functioning of their child, family, and themselves. Mother and clinician accounts revealed in this study have the potential to lead to greater insight and effective practices by clinicians conducting ASD assessments in helping parents to reduce uncertainties about what is going on for their child, find support, and maintain the hopes and dreams they have for their child.
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Appendix A. Recruitment Poster

The Experience of Caregivers and Clinicians in the Assessment of Autism Spectrum Disorder for a Young Child

Are you a parent of a child between the ages of 2 and 6 who received a diagnosis of autism spectrum disorder (ASD) in the past 12 months?

OR

Are you a clinician who diagnosis ASD in young children?

Are you interested in participating in a research study?

The purpose of this study is to understand caregivers’ and clinicians’ experience in the diagnosis of ASD for a young child. This will help us to better understand effective ways to provide support to caregivers when a diagnosis of ASD is being communicated.

If you choose to take part in this project, you will be asked to participate in a one-on-one interview (total time: 2-3 hours). Any parking and/or childcare costs will be reimbursed.

This project is research for a graduate thesis.

If you would like more information, you can call or email us.

Research Team:

Laurie Ford, Ph.D., The University of British Columbia, Phone: XXX-XXX-XXXX
Anna Bowers, B.A. (Hon), The University of British Columbia, Phone: XXX-XXX-XXXX
Appendix B. Parent Information Letter

The Experience of Caregivers and Clinicians in the Assessment of Autism Spectrum Disorder for a Young Child
Letter of Initial Contact for Caregivers

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Dear Caregiver,

We are writing to invite you to be part of a research study about the process of communicating a diagnosis of autism spectrum disorders (ASD) to caregivers. Your participation is very important to help us better understand how to best support caregivers as they receive a diagnosis of ASD for their young child. This letter is intended to introduce you to the study and to describe what it would mean to take part.

What is the purpose of the study?
The purpose of this study is to investigate the perceptions of caregivers and clinicians with regards to the diagnostic process for a child with ASD. A positive experience with the meeting to discuss the child’s assessment results can have an important impact on caregivers’ initial reactions to the diagnosis. Support offered by clinicians has the potential to help caregivers effectively respond to the needs of their recently diagnosed child. There is not much research that has looked at the experience of both caregivers and clinicians in the diagnostic process for ASD. Additionally, there is little information to help guide clinicians in supporting caregivers when a diagnosis of ASD is disclosed. In this study, we want to explore the experience of clinicians in communicating a diagnosis of ASD as well as caregivers’ experience as they first learn of the diagnosis for their child. We hope that the results of this study will help us better understand effective ways to provide support to caregivers when a diagnosis of ASD is given.
What is involved if you take part in the study?
The research study involves taking part in two one-to-one interviews with the researcher. The interviews will take approximately 90 minutes and will be conducted at a time and place you and the researcher agree on. There may be need for a follow-up interview to expand on or clarify information from the first and second interviews. With your permission, the interviews will be audio-recorded and transcribed. Your identity will remain confidential, but parts of and/or direct quotes from the interviews may be used in Ms. Bowers’ thesis without sharing any identifying information. If you would like, a summary of the results will be sent to you once the study is completed.

Taking part in this research project is voluntary and you may refuse to take part or withdraw from the project and/or interview at any time. More details are given in the attached consent form. If you would like to learn more about the study or would like to take part, please contact Anna Bowers by email or phone listed at the beginning of this letter. If we have not heard from you in the next 7 days, we will send you a reminder letter to see if you would like to take part. We look forward to hearing from you.

Sincerely,

Laurie Ford, Ph.D. 
Associate Professor
Principal Investigator

Anna Bowers, B.A.
M.A. Student in School Psychology
Co-Investigator
Appendix C. Clinician Information Letter

The Experience of Caregivers and Clinicians in the Assessment of Autism Spectrum Disorder for a Young Child
Letter of Initial Contact for Clinicians

**Principal Investigator:** Laurie Ford, Ph.D.
Department of Educational & Counselling Psychology, & Special Education
University of British Columbia
Phone: XXX-XXX-XXXX   Email: Name@ubc.ca

**Co-Investigator:** Anna Bowers, M.A. Student
Department of Educational & Counselling Psychology, & Special Education
University of British Columbia
Phone: XXX-XXX-XXXX   Email: Name@ubc.ca

Dear Clinician,

We are writing to invite you to be part of a research study about the process of communicating a diagnosis of autism spectrum disorders (ASD) to caregivers. Your participation is very important to help us better understand how to best support caregivers as they receive a diagnosis of ASD for their young child. This letter is intended to introduce you to the study and to describe what it would mean to take part.

**What is the purpose of the study?**
The purpose of this study is to investigate the perceptions of caregivers and clinicians with regards to the diagnostic process for a child with ASD. A positive experience with the meeting to discuss the child’s assessment results can have an important impact on caregivers’ initial reactions to the diagnosis. Support offered by clinicians has the potential to help caregivers effectively respond to the needs of their recently diagnosed child. There is not much research that has looked at the experience of both caregivers and clinicians in the diagnostic process for ASD. Additionally, there is little information to help guide clinicians in supporting caregivers when a diagnosis of ASD is disclosed. In this study, we want to explore the experience of clinicians in communicating a diagnosis of ASD as well as caregivers’ experience as they first learn of the diagnosis for their child. We hope that the results of this study will help us better understand effective ways to provide support to caregivers when a diagnosis of ASD is given.
What is involved if you take part in the study?
The research study involves taking part in a one-to-one interview with the researcher. The interview will take approximately 90 minutes and will be conducted at a time and place you and the researcher agree on. There may be need for a follow-up interview to expand on or clarify information from the first interview. If you agree, the interviews will be audio-recorded and transcribed. Your identity will remain confidential, but parts of and/or direct quotes from the interview(s) may be used in Ms. Bowers’ thesis without sharing any identifying information. If you would like, a summary of the results will be sent to you once the study is completed.

Taking part in this research project is voluntary and you may refuse to take part or withdraw from the project and/or interview at any time. More details are given in the attached consent form. If you would like to learn more about the study or would like to take part, please contact Anna Bowers by email or phone listed at the beginning of this letter. If we have not heard from you in the next 7 days, we will send you a reminder letter to see if you would like to take part. We look forward to hearing from you.

Sincerely,

Laurie Ford, Ph.D.
Associate Professor
Principal Investigator

Anna Bowers, B.A.
M.A. Student in School Psychology
Co-Investigator
Appendix D. Parent Consent Letter

The Experience of Caregivers and Clinicians in the Assessment of Autism Spectrum Disorder for a Young Child
Consent Letter for Caregivers

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Dear _____ (insert name),

Please read the following letter carefully. This letter is a request for your consent to take part in the study we are doing. This project is a part of a Masters degree in School Psychology at the University of British Columbia for Ms. Bowers. If, after reading the letter, you would like to take part in the study, please sign one copy and give to the interviewer at the interview session. Keep the other copy for your own records.

**Purpose:**
The purpose of this study is to investigate the experience of caregivers and clinicians when a diagnosis of autism spectrum disorder (ASD) is communicated following an assessment for a young child. Clinician support and characteristics have been identified as one of the main avenues to help ensure that caregivers are equipped to meet the needs and demands of their newly diagnosed young child, and in turn facilitate positive outcomes in the child’s functioning. There are few studies that inform future efforts to improve the support provided by clinicians when disclosing a diagnosis of ASD to caregivers. In our study, we want to explore the aspects of the disclosure meeting for ASD that are working well and not working so well, from the perspectives of both caregivers and clinicians in the lower mainland of British Columbia.

**Taking part in our study means:**
1. If you agree to participate in our study, you will take part in two one-on-one interviews about your experience during the assessment of ASD for your child.

2. The interviews will take place at your home or another location that is quiet and works well for you. Each interview will take approximately 90 minutes.
3. The researcher will take notes and the conversation will be audio recorded if you give your consent to do so. After the interview, the researcher will transcribe the audio recording.

4. If you agree, there might be a third follow-up interview to expand or clarify points from the first and second interviews. This could be done by phone.

5. The information we get from the interviews, including interview notes and transcripts, will be used as data in Ms. Bowers’s thesis. All identifying information will remain confidential, but small sections and/or quotes from the interviews may be used in the text of the thesis’s results chapter in a way that ensures you could not be identified.

6. Only the researcher will have access to the information from the interviews. All the information we gather will be stored on password-protected computers and in a locked filing cabinet in Dr. Ford’s office at UBC.

7. Given the nature of the research and interview questions, we do not think the interviews will cause you any discomfort. However, you have the right to decline to answer a specific question, or withdraw from the interview at any time.

8. If you would like, you will receive a copy of the results of the project once it is completed.

Contact for information about the study:
- If you have any questions or would like to know more about this project you may contact Dr. Laurie Ford or Anna Bowers at the email or phone numbers at the top of this page.

Contact for concerns about the rights of research participants:
- If you have any concerns about your treatment or rights as a research participant, you may contact the Research Subject Information Line in the UBC Office of Research Services at 604-822-8598 or if long distance e-mail RSIL@ors.ubc.ca or call toll free 1-877-822-8598.

Consent:
- Taking part in this research project is entirely up to you. It is voluntary and you may refuse to take part or withdraw from the study at any time.
When you sign below it means that you consent to take part in this research project. When you sign below it also means that you have received a copy of this consent (pages 1, 2 & 3) for your own records.

**PLEASE CHECK ONE:**

___ Yes, I would like to take part in this study.

___ No, I do not want to take part in this study.

**IF YES:**

___ Yes, it is ok for the interview to be audio-recorded.

___ No, you may not audio-record the interview.

___________________________________
Your Name (Please Print)

___________________________________                         ____________________________
Your Signature                                                                         Date
Appendix E. Clinician Consent Letter

| The Experience of Caregivers and Clinicians in the Assessment of Autism Spectrum Disorder for a Young Child |
| Consent Letter for Clinicians |
| Principal Investigator: Laurie Ford, Ph.D. |
| Department of Educational & Counselling Psychology, & Special Education |
| University of British Columbia |
| Phone: XXX-XXX-XXXX Email: Name@ubc.ca |
| Co-Investigator: Anna Bowers, M.A. Student |
| Department of Educational & Counselling Psychology, & Special Education |
| University of British Columbia |
| Phone: XXX-XXX-XXXX Email: Name@ubc.ca |

Dear _____ (insert name),

Please read the following letter carefully. This letter is a request for your consent to take part in the study we are doing. This project is a part of a Masters degree in School Psychology at the University of British Columbia for Ms. Bowers. If after reading the letter, you would like to take part in the study, please sign one copy and give to the interviewer at the interview session. Keep the other copy for your own records.

Purpose:
The purpose of this study is to investigate the experience of caregivers and clinicians when a diagnosis of autism spectrum disorder (ASD) is communicated following an assessment for a young child. Clinician support and characteristics have been identified as one of the main avenues to help ensure that caregivers are equipped to meet the needs and demands of their newly diagnosed young child, and in turn facilitate positive outcomes in the child’s functioning. There are few studies that inform future efforts to improve the support provided by clinicians when disclosing a diagnosis of ASD to caregivers. In our study we want to explore the aspects of the disclosure meeting for ASD that are working well and not working so well, from the perspectives of both caregivers and clinicians in the lower mainland of British Columbia.

Taking Part in our Study Means:

9. If you agree to take part in our study, you will participate in a one-on-one interview about your experiences communicating a diagnosis of ASD to caregivers.

10. The interview will take place at your place of work on a date and time that works for you. The interview will take approximately 90 minutes.
11. The researcher will take notes and the conversation will be audio recorded if you give your consent to do so. After the interview, the researcher will transcribe the audio recording.

12. If you agree, there might be a follow-up interview to expand or clarify points in the first interview. This could be done by telephone.

13. The information we get during the interview(s), including interview notes and transcripts, will be used as data in Ms. Bowers’s thesis. Your identity will remain confidential, but excerpts and/or direct quotes from the interview(s) may be used anonymously in the text of the thesis’s results chapter.

14. Only the researchers will have access to the information from the interview(s). Interview notes, transcripts, and audio recordings will be stored in password-protected computers and backed-up in a locked filing cabinet in Dr. Ford’s office at UBC.

15. Given the nature of the research and questions posed during the interview, it is not expected that you will experience any discomfort. However, you have the right to decline to answer a specific question, or withdraw from the interview at any time.

16. If would like, you will receive a copy of the results of the project once it is completed.

Contact for information about the study:
• If you have any questions or would like to learn more about this project you may contact Dr. Laurie Ford or Anna Bowers at the email or phone number at the top of this page.

Contact for concerns about the rights of research participants:
• If you have any concerns about your treatment or rights as a research participant, you may contact the Research Subject Information Line in the UBC Office of Research Services at 604-822-8598 or if long distance e-mail RSIL@ors.ubc.ca or call toll free 1-877-822-8598.

Consent:
• Taking part in this research project is entirely up to you. It is voluntary and you may refuse to take part or withdraw from the study at any time.
When you sign below it means that you consent to take part in this research project. When you sign below it also means that you have received a copy of this consent form (pages 1, 2 & 3) for your own records.

<table>
<thead>
<tr>
<th>PLEASE CHECK ONE:</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>____ Yes, I would like to take part in this study</td>
<td></td>
</tr>
<tr>
<td>____ No, I do not wish to take part in this study.</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>IF YES:</th>
<th></th>
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</thead>
<tbody>
<tr>
<td>____ Yes, it is ok for the interview to be audio-recorded.</td>
<td></td>
</tr>
<tr>
<td>____ No, it is not ok for the interview to be audio-recorded.</td>
<td></td>
</tr>
</tbody>
</table>

___________________________________
Your Name (Please Print)

___________________________________                          ______________________________
Your Signature                          Date
Appendix F. Parent Background Questionnaire

THE EXPERIENCE OF CAREGIVERS AND CLINICIANS IN THE ASSESSMENT OF A YOUNG CHILD WITH AUTISM SPECTRUM DISORDER

CAREGIVER BACKGROUND QUESTIONS

Thank you for your willingness to take part in our study. Before we start our interview, please take a few minutes to answer a few questions about your child, your family and your background. Some questions might be a bit sensitive. If you are not comfortable answering a question, it is ok to skip it. Answer these questions with regards to your child with ASD.

What is your child’s age? _____ Years _____ Months

What is your child’s sex? _____ Male _____ Female _____ Other

What is your child’s ethnic background? ________________________________

What is your child’s first language? ________________________________

What is the primary language spoken in your home? __________________

Caregiver & Family Background Information

Are you the primary or main caregiver of the child with ASD in your home?
_____ Yes _____ No

What is your relationship to the child?
_____ Biological Mother
_____ Biological Father
_____ Grandmother
_____ Grandfather
_____ Other Legal Guardian (please specify): ____________________________
_____ Other (please specify): ____________________________

What is your sex?
_____ Male _____ Female _____ Other

What is your age? _____ Years

What is your first language? ________________________________
What best describes your current marital status?
- Single Parent
- Married/Common-Law
- Separated/Divorced
- Other

How many people currently live in your home?
- Number of Adults (including you)
- Number of children and youth (19 or younger)

Are there other adults living in your home and providing a caregiving role for you child with ASD? Yes _____ No

What is the highest level of education for each of the following caregivers currently living in your home (complete for all the apply)?

<table>
<thead>
<tr>
<th></th>
<th>You</th>
<th>Other Caregiver (specify):</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than Grade 9</td>
<td>_____</td>
<td>_____</td>
</tr>
<tr>
<td>Less than High School Diploma</td>
<td>_____</td>
<td>_____</td>
</tr>
<tr>
<td>High School Diploma</td>
<td>_____</td>
<td>_____</td>
</tr>
<tr>
<td>Some college, trade school, university</td>
<td>_____</td>
<td>_____</td>
</tr>
<tr>
<td>College/trade school diploma/certificate</td>
<td>_____</td>
<td>_____</td>
</tr>
<tr>
<td>Bachelors Degree</td>
<td>_____</td>
<td>_____</td>
</tr>
<tr>
<td>Post-Baccalaureate Diploma or Graduate Degree</td>
<td>_____</td>
<td>_____</td>
</tr>
</tbody>
</table>

Please describe the current employment status for each of the following caregivers currently living in your home:

<table>
<thead>
<tr>
<th></th>
<th>You</th>
<th>Other Caregiver (Specify)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Working full-time</td>
<td>_____</td>
<td>_____</td>
</tr>
<tr>
<td>Working part-time</td>
<td>_____</td>
<td>_____</td>
</tr>
<tr>
<td>Full-time student</td>
<td>_____</td>
<td>_____</td>
</tr>
<tr>
<td>Part-time student</td>
<td>_____</td>
<td>_____</td>
</tr>
<tr>
<td>Not employed</td>
<td>_____</td>
<td>_____</td>
</tr>
</tbody>
</table>

What best describes your annual (combined) household income? (If you are not comfortable answering this question it is ok to leave it blank).
- Less than $14,999
- $15,999 to 19,999
- $20,000 to $29,999
- $30,000 to $39,999
- $40,000 to $59,999
- $60,000 or more
Your Child’s Assessment and Diagnosis of ASD

At what age was your child diagnosed with ASD? _____ Years _____ Months

Who made the initial formal diagnosis?

_____ Psychologist  _____ Psychiatrist  _____ Family Physician

_____ Paediatrician  _____ Other (please specify): ____________________________

_____ I do not recall

What was the approximate date of the meeting at which the diagnosis of ASD was made? - ______________

What type of support services does your child currently receive? (check all that apply)

_____ Home-based behaviour intervention

_____ Private speech-language pathology services

_____ Private occupational therapy services

_____ Supported Child Development Consultant

_____ Strong Start

_____ School-based speech language services

_____ School-based occupational therapy services

_____ Other (please specify): _______________
Appendix G. Clinician Background Questionnaire

THE EXPERIENCE OF CAREGIVERS AND CLINICIANS IN THE ASSESSMENT OF A YOUNG CHILD WITH AUTISM SPECTRUM DISORDER

CLINICIAN BACKGROUND QUESTIONS

Thank you for your willingness to take part in our study. Before we start our interview, please take a few minutes to answer a few questions about your background.

What is your age? __________
What is your sex? ___ Male ___ Female ___ Other

What is your highest educational degree:
___ Masters Degree ___ PhD/EdD/PsyD
___ Post Doctoral ___ MD _____ Other (specify): ________________

What is the area of specialty for your highest degree? __________________________

What year did you complete your highest degree? _____________________________

What is your current occupation? __________________________________________

How many years have you worked that field? _________________________________

What is your current primary work setting (e.g. private practice, hospital, mental health clinic)? ____________________________

How many years have you worked in that setting: _____

What is the total the number of years you have worked with children with ASD? ______

How many years have you conducted diagnostic assessments for ASD? ______
Appendix H. Parent Interview Guide

CAREGIVER INTERVIEW GUIDE

Guide for 1st Interview

Introduction and Orientation:
- Introduction of self and research study.
- Review and sign consent form.
- Give caregiver information on community support resources.
- Give caregiver Background Information Questionnaire to complete.

Interview Questions:
1) What was going on around the time of your child’s assessment for ASD?
2) Tell me about some emotions or feelings you had before pursuing an assessment.
3) What was the assessment process like?
4) Tell me about the meeting with the clinician after the assessment for ASD was completed.
   [Potential Follow-Up Questions]
   - What did the clinician tell you about your child’s functioning in terms of what the assessment findings were? Did this fit with your perceptions?
   - What was it like for you as the clinician was telling you that your child has ASD?
   - How did you participate in this meeting? What did that mean to you?
   - Tell me about any ways your clinician provided support and guidance.
   - How would you describe your feelings immediately following the meeting?
5) What would you say worked well or was positive about the meeting?
6) What do you think could have been done differently during this meeting?
7) What strengths did you bring to the disclosure meeting (final meeting where you learned the results of the assessment)? Describe any strengths of the clinician who communicated the diagnosis/information?
Guide for 2nd Interview
1) What does a diagnosis of ASD mean for your child?
   • For you?
   • For your family?
2) Tell me about the support your child is currently receiving.
3) Tell me about the nature of support you are receiving as a caregiver of a child with ASD.
4) What advice would you give clinicians with regards to the assessment process for a child with ASD?
5) What advice would you give clinicians with regards to the way they communicate a diagnosis of ASD?
6) What advice would you give to parents who are seeking an assessment/diagnosis of ASD for their child?

Guide for 3rd Interview (if needed)
1) Is there any information in the summary that you believe is inaccurate or was misunderstood?
2) Is there anything that we discussed the previous times we met that you want to talk more about?
3) Is there anything that you believe you didn’t get a chance to discuss the first or second time we met?
4) Please expand/elaborate on what you meant by _________?
5) When you talked about ____________ what was that like for you?
Appendix I. Clinician Interview Guide

CLINICIAN INTERVIEW GUIDE

Guide for 1st Interview

Instruction and Orientation:
• Introduction of self and research study.
• Review and sign consent form.
• Give clinician Background Information Questionnaire to complete.

Interview Questions:
1) Tell me about the training and experiences you have had in working with children with ASD and their parents.
2) Tell me about the training and experiences you have in diagnosing children with ASD.
3) What are some common referral concerns that caregivers present to you when seeking an assessment for ASD for their child?
4) Tell me about the process or approach you take when assessing a child for ASD.
5) What are some strengths that caregivers bring when they come for an assessment for their child?
6) What do you perceive as some of the greatest challenges caregivers have during the assessment and diagnosis process?
7) Tell me about the process or approach you use when communicating a diagnosis of ASD to caregivers.
8) What are some of your strengths in communicating an ASD diagnosis?
9) What are some challenges you experience in communicating an ASD diagnosis?
10) How would you say parents generally react when you inform them their child has ASD?
11) Tell me about the ways in which you attempt to provide support and guidance to caregivers during the meeting after the assessment.
12) What would you work well during the meeting in which you disclose a diagnosis of ASD to parents?
13) What do you think could be done differently during this meeting?

Guide for 2nd Interview (if needed)
6) Is there any information in the summary that you believe is inaccurate or was misunderstood?
7) Is there anything that we discussed the first time we met that you want to talk more about?
8) Is there anything that you believe you didn’t get a chance to discuss the first time we met?
9) Please expand/elaborate on what you meant by ________?
10) When you talked about __________ what was that like for you?
**Appendix J. Mother Themes With Sample Quotes**

<table>
<thead>
<tr>
<th>Phase</th>
<th>Theme/Subthemes</th>
<th>Example from Data</th>
</tr>
</thead>
</table>
| Before the Assessment | Something’s not right: Is it me? Is it a phase? | **Quirky or something else?**  
We’ve always had this hmm is this just quirkiness…then saying okay there’s really something going on…let’s look into this.  
**“Dreams shattered”**  
Sad, hopeless, like you have all these hopes and dreams for your child- you know for their future- and they were just pretty much all shattered. |
| Suspicions: Is it autism? | “No exposure” | I had next to no exposure to autism.  
**“Read up on it”**  
Symptoms were just getting worse and I was becoming more and more anxious about it. And just starting to read up on…it could be autism, it could be autism. |
| Isolation: Can’t go anywhere | “Had to stay home” | Frustration…a feeling of isolation because I felt like I couldn’t take her to these kind of playgroup things. We tried but she just didn’t seem to do very well…We had to stay home. That led to a real feeling of isolation and depression in some sense.  
**Haven’t sought**  
I haven’t really sought out [social activities] because he doesn’t do well in groups. |
| Response by others: No way or I think you are right | “Genuine concerns…shut up” | I had very very strong feelings…I just had to trust my gut. Even though everyone else around me was saying like he’s fine, he’s fine, he’s fine. I’m like shut up. Like don’t say that. I’m his mother and I have genuine concerns and stop trying to placate my feelings…that doesn’t make me feel better. I need support in this decision. Not like, “Oh you’re just reading into things.”  
**“If concerned, call”**  
An extended family member…said, if you’re concerned just call…so I figured well okay she sees kids all the time and she was validating what I was concerned with… She obviously felt that I had some valid concerns. |
# Appendix J. Mother Themes With Sample Quotes (Continued)

| Before the Assessment | Response by others: No way or I think you are right | “No way, not autism”
|-----------------------|-----------------------------------------------------|--------------------------------------------------|
|                       | Agreement with concerns Dismissal of concerns       | The woman who came to observe him came and talked to me…I had raised the whole idea of Asperger’s, High Functioning Autism and she said, oh no way. I’ve worked with kids and even with high functioning and there’s no way. And you want to believe that…So we took that as okay great…we’ll take that at face value because you’re supposed to know…in hindsight I don’t think she should have ever said that. She’s not a trained psychologist. She could’ve said well he presents differently from most of the kids I work with but if you’re concerned see a paediatrician.
|                       |                                                     | “Think you’re right…make referral”
|                       |                                                     | [Family Physician] heard my concerns…she said I think you’re right. I’ve noticed these things and I will check it out…said it sounds like we want to investigate so then we filled out some questionnaires…then she looked them over and said yes I’ll make a referral, there are too many things here that stand out.
| Waiting: Unable to get therapy started | “Already have belief” | I’m here for a reason because I already have the belief [that it’s autism] myself…I don’t want to wait any longer “Waiting to start therapy”
|                       |                                                     | My concern was out of all the things that I read: early intervention is best, early intervention is best. So the frustrating thing was waiting so long to start his therapy “Wanted to see again”
|                       |                                                     | We went to the paediatrician and he said he didn’t want to refer us right away. He wanted to see us again in 3 months. I think it was to see if she had changed or to see how things were going so…what was I going to do? I was like, okay, whatever.
|                       |                                                     | “Lost funding”
|                       |                                                     | Once you’ve seen one kid on the spectrum, you’ve seen one kid on the spectrum. So for us, there was a bit of upset about saying [it’s not autism]…we might’ve lost a year of funding…So that was kind of the most anxiety came out of that for us.
| During the Assessment | Getting the diagnosis: Validating yet evoking worry | “Prepared for diagnosis”
|                       |                                                     | I’d prepared myself for this diagnosis because I was 99.9% sure that that was what they were going to tell me.

<p>| Reaction | Meaning |</p>
<table>
<thead>
<tr>
<th>During the Assessment</th>
<th>Getting the diagnosis: Validating yet evoking worry</th>
<th>“Justified”</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Reaction Meaning</td>
<td>They basically are confirming what I feel like I already knew in my heart what was going on. I felt oddly justified that my efforts weren’t all in vain because I probably would’ve lost my mind if they’d told me he wasn’t autistic. So it was just a feeling of relief and a feeling of yeah, okay, anxiety because now I had this big road ahead of me, you know, of putting this team together and getting funding and working that out.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“Challenge”</td>
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<tr>
<td></td>
<td></td>
<td>Challenge, patience…patience. Diligence. Sometimes I’m just a bit too diligent, sticking to the program…I feel like we need to maintain this forward motion</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“Possibilities; knowing how to support”</td>
</tr>
<tr>
<td></td>
<td></td>
<td>The diagnosis means possibilities….knowing better how to support him, how to scaffold things, and you know opening the door to getting some funding.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“Frame differently”</td>
</tr>
<tr>
<td></td>
<td></td>
<td>now it’s more like yes it’s exhausting, yes I wish we didn’t have that issue, but at the same time I can frame it differently for myself.</td>
</tr>
<tr>
<td>Different beliefs than spouse: Can’t deny the challenges</td>
<td>“Contention”</td>
<td>We fought a lot. There was a point of contention in our relationship for a good two years…he was not having any of it…You can’t deny the challenges we face. You can’t just pass them off as a phase anymore. Like that just doesn’t fly with me.</td>
</tr>
<tr>
<td>Certainty or denial</td>
<td>“Not autism”</td>
<td>He didn’t think it was autism right up until that day.</td>
</tr>
<tr>
<td>Contention</td>
<td></td>
<td></td>
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<tr>
<td>Delayed acceptance</td>
<td></td>
<td></td>
</tr>
<tr>
<td>What the clinician did and said: Efficient and personable</td>
<td>“Clear and factual”</td>
<td>I felt that they were very clear about the things that were symptoms. It wasn’t just like well we think this is what’s going on but we need to think about it more. They were very clear about the specific things that were symptoms.</td>
</tr>
<tr>
<td>Checking-in</td>
<td>“Saw who he was”</td>
<td>Warm demeanour, tuned in. That’s the one thing I actually told her in the email. I really felt like she saw who he was so to us that was really important. So she described exactly the boy that we know, that she had seen…she said he was great, he was these strengths and these interests.</td>
</tr>
<tr>
<td>Clear and factual</td>
<td>“Straightforward”</td>
<td>Straightforward, to the point, these are our findings, this is what we feel the child needs… I left having all the tools I needed to move forward. Now the journey begins.</td>
</tr>
</tbody>
</table>
| During the Assessment | Support for parent: Helpful but not enough | “Online; Knowledgeable”  
The only support for myself is through support groups on Facebook…that’s probably been the most, I would say, helpful… I’ve actually found people on there that are quite knowledgeable and quite experienced…been in the system for a few years.  
“Stories, solutions, coping”  
Listening to their stories, seeing what their solutions to certain problems are, how they cope, what certain situations.  
“Nobody understood”  
Lack of support because nobody truly understood…even my sister-in-law. She kind of made a comment one time: well you guys leave early. And I’m like, well this is why we leave early and she said, oh I had no idea…I had no idea that that’s what you guys were going through. I understand now why you leave early. |
| --- | --- | --- |
| Moving Forward | Readiness to set-up treatment: Let’s get started or feeling numb  
Just needed diagnosis  
Daunting/overwhelming | “In operation mode”  
I don’t think I’ve yet done that grieving because there’s so much you need to do, you’re just in operation mode, you’re not in thinking or feeling mode so I don’t think I’ve done that….it’s more let’s get started, let’s get answers.  
“Numb and disorganized”  
I felt really numb…there were a few days where I was just like ugh…just nothing. I didn’t feel anything, I just felt kind of bad and disorganized and you know. |
|  |  |  |
|  | Hopes and Fears: Being accepted and achieving milestones | How people will see him  
Worries and that people thinking he’s selfish and he’s such a caring little guy so knowing people might not see him for who he is, that really upsets me  
“Enough support”  
I have anxiety over whether he’s going to have enough support in school cause so far at this point, he’s going to have to share support. |
|  | Support: Availability and accessibility  
What’s available  
What’s needed and challenges | “Counsellor”  
I talked to T’s counsellor once and my husband’s going to talk to her next week so just sort of how are we dealing and that’s been helpful. I’d love to do more of that- get my own person to talk to but again, that’s budget thing. We’ll see.  
“Could be more support”  
No I don’t [think there’s sufficient support] actually because we’re missing the behaviour intervention aspect and we’re missing a real consultant who’s supportive of us and who is a part of our team…respite is the other thing we’ve been [looking into]…but like I said, I don’t feel we’ve got- I feel like there could be more in the way of support. |
## Appendix K. Clinician Themes With Sample Quotes

<table>
<thead>
<tr>
<th>Phase</th>
<th>Theme/Subthemes</th>
<th>Example from Data</th>
</tr>
</thead>
<tbody>
<tr>
<td>Training &amp; Experience</td>
<td>Previous positions: Revealing need and interest</td>
<td>“Apparent need” I started working as a school psychologist…then I started private practice…a lot of our referrals are for autism assessment or treatment or intervention so it became apparent there was a lot of need for that.</td>
</tr>
<tr>
<td></td>
<td>Education: Learning procedures more than clinical skills</td>
<td>“Less focus on communicating diagnosis” Overall when I look at all of my training I think is in using the diagnostic tools and how to pull together the various information from sources you’ve collected and coming up with your diagnosis. There is definitely I think less focus and emphasis on how to communicate that diagnosis…less with a specific focus on ASD. “Sensitivity is a clinical skill” But the way that you do it, or the sensitivity that you do it, or…you know, I guess it’s a clinical skill.</td>
</tr>
<tr>
<td>Perceptions of ASD families: Reacting rather than causing</td>
<td></td>
<td>“Not causing the disability” You’re kind of an ally with them…there’s a different kind of therapeutic alliance that forms between a therapist and a family when you’re working on something like ASD. The parents aren’t doing anything to cause the disability. They’re often reacting to it. “Stress to get going early” Parents not only have to get a treatment program up and running, and we know early intervention is key, but there’s a stress to get it going really early. If it’s diagnosed late-oh my gosh, I missed all these critical years of treatment. “Smart consumers” They have to be smart consumers as well because there are a lot of other things out there that don’t have much evidence but seem to be sold as this is going to cure your child.</td>
</tr>
<tr>
<td>Before the Assessment</td>
<td>Referral concerns: Quirky or something else?</td>
<td>“There are…so is it?” There’s some attention problems, there’s some repetitive behaviours, is it ASD, is it tics, is it just stereotypic behaviour? And difficulties with social, communication, reciprocity…intellectually gifted. So is it something related to that? Are they just a little quirky?</td>
</tr>
</tbody>
</table>
Appendix K. Clinician Themes With Sample Quotes (Continued)

<table>
<thead>
<tr>
<th>Before the Assessment</th>
<th>Reasons for seeking: Answers and help</th>
<th>“Still wondering”</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td><strong>Way to get support</strong></td>
<td>We’ve had this assessment and it’s still a concern. We still kind of wonder…so often in private practice, they’re the ones who are curious.</td>
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<tr>
<td></td>
<td><strong>Second opinion</strong></td>
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<table>
<thead>
<tr>
<th>Who prompted the referral: Concerns because a reality</th>
<th>“Friend”</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Some families come too because they’ve been referred by a friend who has a child on the autism spectrum. And their friend says to them, “You know, your child has a few of these mannerisms and things that my guy did when he was that age and maybe you should go get an assessment.”</td>
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<table>
<thead>
<tr>
<th></th>
<th>“More up to speed”</th>
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<tbody>
<tr>
<td>Physicians are a lot more up to speed these days. Teachers are a lot more up to speed.</td>
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<table>
<thead>
<tr>
<th></th>
<th>“Starts with doctor”</th>
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<tbody>
<tr>
<td>The medical community would be the largest referring group…most of the time it starts with the parents approaching the family doctor about behavioural concerns…Some parents come in and their physician has told them straight up that they’re concerned about autism.</td>
<td></td>
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<thead>
<tr>
<th>Suspicions of ASD: Research planted the seed</th>
<th>“Some likelihood”</th>
</tr>
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<tbody>
<tr>
<td>I would say most of them come with the idea that there’s some likelihood that their child will receive that diagnosis.</td>
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<thead>
<tr>
<th></th>
<th>“Turn over every stone”</th>
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<tbody>
<tr>
<td>The parents are coming here going, listen I want you to turn over every stone about this autism thing because I really think it is and the teacher really thinks it is.</td>
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<table>
<thead>
<tr>
<th></th>
<th>“Go on the internet”</th>
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<tbody>
<tr>
<td>Finding out what they know about autism [is important] because a lot of parents do go on the internet…accurate or not accurate.</td>
<td></td>
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</tbody>
</table>
### Appendix K. Clinician Themes With Sample Quotes (Continued)

<table>
<thead>
<tr>
<th>During the Assessment</th>
<th>How families are presenting:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Varied preparedness</td>
</tr>
<tr>
<td></td>
<td>Done the emotional groundwork</td>
</tr>
<tr>
<td></td>
<td>Hard time dealing with pressures</td>
</tr>
<tr>
<td>“Wrapped mind and heart around”</td>
<td>Parents come in having already wrapped their minds and hearts around the possibility and they’re wanting confirmation or disconfirmation of that. So we see a lot of families come in prepared for the process.</td>
</tr>
<tr>
<td>“Struggling”</td>
<td>I wouldn’t say many parents come in really calm…that they’ve been struggling for a while in terms of trying to make sense of what’s going on with their child and how to best support them.</td>
</tr>
<tr>
<td>“Don’t feel you can relate”</td>
<td>there are things about having a child with a disability that are naturally isolating, you know where you don’t feel you can relate to your neighbour or other people don’t understand, or your child makes a kafuffle whenever you go out in public.</td>
</tr>
<tr>
<td>“Shame”</td>
<td>feelings of shame or somehow that they’re at fault or that their parenting has caused these atypical behaviours in their child and perhaps bringing a lot of guilt to it…the feeling of inadequacy, that perhaps it’s because they’ve done something wrong or haven’t parented right or things like that.</td>
</tr>
<tr>
<td>“Stress”</td>
<td>Most parents have stress but parents of kids on the spectrum who don’t have the answers yet are still dealing from that so higher stress level. And you know some parents get outright depressed, marriages break up…that’s not necessarily part of the assessment process it’s part of living in that world or having a child with a disability and how stressful it is on your marriage. Hard on your own mental health, hard on the marriage.</td>
</tr>
<tr>
<td>Informing about the process: Steps and bringing up ASD</td>
<td>“Psychoeducation around process”</td>
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<td></td>
<td>I think also that parents are worried you’re going to make a decision by meeting with their child only once. So there is definitely I think some psychoeducation around the diagnostic process.</td>
</tr>
<tr>
<td>“Throwing autism out there”</td>
<td>in the first interview with the parents I might actually bring it up then. Say, has anyone ever mentioned autism…Some of the things he’s doing are smack of that or they remind me a little bit of that so I’m just throwing that out there at this point. I’m not sure. I’m just kind of seeing some things.</td>
</tr>
</tbody>
</table>
### Appendix K. Clinician Themes With Sample Quotes (Continued)

<table>
<thead>
<tr>
<th>During the Assessment</th>
<th>Supporting parents during sessions: Concerns and strategies</th>
<th>“Helping them comes at the end”</th>
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</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>I think [helping the parents] mostly comes at the end when I do the feedback and work with them.</td>
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<tr>
<td></td>
<td></td>
<td><strong>“Give suggestions”</strong></td>
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<tr>
<td></td>
<td></td>
<td>If parents ask me something specific about their child refusing to do something or they’re having a hard time with compliance issues, for example, then I will make some suggestions.</td>
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<tr>
<td></td>
<td></td>
<td><strong>“Get to what’s going on”</strong></td>
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<td></td>
<td></td>
<td>Parents won’t always say to you, “I’m feeling stressed out” or “I’m really not happy” but it…you know…eventually, if we do enough talking, we can kind of get around to that…what’s going on for some parents and then it’s kind of helping them find their own happiness.</td>
</tr>
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</table>

<table>
<thead>
<tr>
<th>Communicating the diagnosis: Confirming but still a big deal</th>
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<tbody>
<tr>
<td><strong>Strategies used</strong></td>
</tr>
<tr>
<td><strong>Order of presenting results and diagnosis</strong></td>
</tr>
<tr>
<td><strong>Considering audience</strong></td>
</tr>
<tr>
<td><strong>Instilling hope</strong></td>
</tr>
<tr>
<td>“Start thinking: a lot of symptoms”</td>
</tr>
<tr>
<td>I think they’re starting to process it already before you say that together, when we look at these symptoms and the pattern of these symptoms from all these places we looked at, there is strong evidence that your child has ASD.</td>
</tr>
<tr>
<td>“Sitting with them”</td>
</tr>
<tr>
<td>There definitely are those situations where the parents aren’t ready to hear it…and so often it’s kind of just sitting with them and yeah this is difficult.</td>
</tr>
</tbody>
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<table>
<thead>
<tr>
<th>Parents’ reaction: From grief to relief</th>
</tr>
</thead>
<tbody>
<tr>
<td>“Confirming”</td>
</tr>
<tr>
<td>they’ve already maybe gone through a lot of the emotional ups and down of knowing something’s different and certainly confirming what that is I think is probably helpful for them.</td>
</tr>
<tr>
<td>“Now what?”</td>
</tr>
<tr>
<td>That’s a big piece too, is: okay, we have this diagnosis, now what?... in terms of the resources in the community, resources that look at evidence-based treatment.</td>
</tr>
<tr>
<td>“Chronic sorrow; bereavement model”</td>
</tr>
<tr>
<td>terms like chronic sorrow and using sort of the bereavement model to describe some of the reactions that parents go through.</td>
</tr>
</tbody>
</table>
Appendix K. Clinician Themes With Sample Quotes (Continued)

<table>
<thead>
<tr>
<th>Moving Forward</th>
<th>Guidance through resources: Practical rather than emotional support</th>
<th>Need/want the tools</th>
</tr>
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<tbody>
<tr>
<td></td>
<td>Most what families need to know is okay, here’s your diagnosis, here’s a form I’ve completed along with your assessment. And here’s the telephone number…that you access funding and here’s…we have a booklet…</td>
<td></td>
</tr>
<tr>
<td></td>
<td>“Connecting with other families”</td>
<td>I know from feedback we’ve had from families, that for them to just connect with other families who have a child with the same diagnosis.</td>
</tr>
<tr>
<td></td>
<td><strong>Got what I need or “take time to digest”</strong></td>
<td>I guess for some people, they’ve already found out a lot of information so they sort of know, “Okay this is what I’ve got now and I need this piece of paper to go do what I need to do.” And they completely know all of that…But for others, yeah it does take time for them to digest it and they’ll come back another time.</td>
</tr>
<tr>
<td></td>
<td><strong>“Adjust”</strong></td>
<td>Being able to adjust how I’m speaking to them depending on whether they’re in a whole lot of denial, whether they’re completely on board.</td>
</tr>
<tr>
<td></td>
<td><strong>“Step back”</strong></td>
<td>Let’s step back from the label and what that means and let’s describe these behaviours and I find that that helps parents to understand that we’re talking about this child.</td>
</tr>
</tbody>
</table>
Appendix L. Perceptions of Strengths & Challenges With Sample Quotes

<table>
<thead>
<tr>
<th>Parent Perceptions</th>
<th>Parent Strengths</th>
</tr>
</thead>
<tbody>
<tr>
<td>“Research”</td>
<td>I would say having the research that I did. That really helped me.</td>
</tr>
<tr>
<td>“Focus”</td>
<td>I’m going to focus on what he needs, really, specifically.</td>
</tr>
<tr>
<td>Good communicators</td>
<td>We connected quite a bit with his teacher and talked with her about the process.</td>
</tr>
<tr>
<td>Strong feelings</td>
<td>I had very very strong feelings about [child]…had to trust my gut.</td>
</tr>
</tbody>
</table>

| Parent Challenges  | |
|--------------------| “Don’t dismiss” |
|                    | I’ve heard from a lot of moms…family doctor just didn’t believe that their concerns were valid…Like don’t just dismiss a mother’s instinct. |
|                    | “Brushed off concerns” |
|                    | I was talking to [OT and SLP] about what I was researching and my concerns and both ladies brushed it off and said, “You don’t have anything to worry about. I work with autistic children all the time and your child doesn’t have autism”…extremely frustrating to hear. |
|                    | “Overwhelmed” by information |
|                    | I just said: What now? What do I do? Where do I go from here? Who do I talk to? And they basically just gave me all this information…Binder, folder like that, stacked full of pamphlets, forms…I was overwhelmed. |

| Clinical Strengths | |
|--------------------| “Saw who he was” |
|                    | Warm demeanour, tuned in. That’s the one thing I actually told her in the email. I really felt like she saw who he was so to us that was really important. So she described exactly the boy that we know, that she had seen…she said he was great, he was these strengths and these interests. |
|                    | “Clear and factual” |
|                    | I felt that they were very clear about the things that were symptoms. It wasn’t just like well we think this is what’s going on but we need to think about it more. They were very clear about the specific things that were symptoms. |
|                    | “Straightforward” |
|                    | Straightforward, to the point, these are our findings, this is what we feel the child needs…they gave me all the tools. I left having all the tools I needed to move forward with it. You know, now the journey begins. |
Appendix L. Perceptions of Strengths & Challenges With Sample Quotes (Continued)

<table>
<thead>
<tr>
<th>Clinician Perceptions</th>
<th>Parent Strengths</th>
</tr>
</thead>
<tbody>
<tr>
<td>“Keen gut feeling”</td>
<td>their increase knowledge of developmental disorders, overall. I think that majority of parents know their children really well and usually have a really keen gut feeling that they might not be accurate that it’s ASD but accurate that something’s going on for their child that they’re concerned about and have a right to be concerned.</td>
</tr>
<tr>
<td>“Organized; done research; empowered”</td>
<td>highly organized and on the ball. And they’ve done their research and they’re...they think yeah, this totally fits for their child, and what can we do to access all that support and funding that’s available once they receive a diagnosis. Things like that. So yeah, they bring a lot of positive to it...quite empowered.</td>
</tr>
<tr>
<td>“Try to adapt”</td>
<td>whether it’s been successful or not, have been doing things to try and adapt their environment and themselves to their child.</td>
</tr>
<tr>
<td>“Beat down, keep going”</td>
<td>I think resilience, like resourcefulness, is a big thing...don’t give up easily...When you get beat down, for kids you’re going to keep going.</td>
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</tbody>
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<table>
<thead>
<tr>
<th>Parent Challenges</th>
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<tbody>
<tr>
<td>“Hard on mental health and marriage”</td>
</tr>
<tr>
<td>“Depressed”</td>
</tr>
<tr>
<td>“Responsibility”</td>
</tr>
<tr>
<td>“Not on their radar”</td>
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<tr>
<td>“Watch their kid suffer”</td>
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</tbody>
</table>
Appendix L. Perceptions of Strengths & Challenges With Sample Quotes (Continued)

<table>
<thead>
<tr>
<th>Clinician Perceptions</th>
<th>Clinician Strengths</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>“Sensitive; attuned”</td>
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<td></td>
<td>I think being sensitive to where the family is at in that moment. Like I said, sometimes they’re ready to hear the news. I don’t go through the thing with every family…you have to be very sensitive and attuned to where the family is at in that whole process. It sort of shifts over the course of the feedback so- and if you’re attuned enough, you’re usually going to get people showing some real feelings and you gotta be able to manage that a little bit so it’s just the clinical skills you pick up as you’re going through the years.</td>
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<tr>
<td></td>
<td>“Take time”</td>
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<td></td>
<td>I think there’s a lot of pressure on young practitioners to feel they can just go in there and get the diagnosis and do it all very confidently, but one thing I’ve learned over the years is sometimes you just need to take more time.</td>
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<tr>
<td></td>
<td>“Hope; Where to go next”</td>
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<td></td>
<td>trying to instil hope with these families. That can be in terms of, we’ve done a lot of research in this area and we know what treatments work best for most children or many children. Can be hopeful and give them a sense of, okay there’s something we know we can do….that piece of where to go next.</td>
</tr>
<tr>
<td></td>
<td>“Clear and confident:”</td>
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<td></td>
<td>I think being clear and confident- if you are confident in your decision, then being clear and if you’re not, being frank that this is- it’s inconclusive but once you’ve decided, communicating it in a clear way so families can leave not was it was it not? So they have a clear direction to go.</td>
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<thead>
<tr>
<th>Clinician Challenges</th>
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<tbody>
<tr>
<td></td>
<td>“Preconceived ideas”</td>
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<td></td>
<td>Often the greatest challenge is that they also have a distinct bias…they will come with sort of some preconceived ideas, whether their child is autistic or not. And you have to really work with that part of them…if it’s not in line with the findings then that’s the challenging part.</td>
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<tr>
<td></td>
<td>Personal experience</td>
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<td></td>
<td>What we bring to these interactions with parents. Like I’m sure it’s different for practitioners who have family members on the autism spectrum and umm I would imagine that would be more difficult in some ways but also easier to be more empathetic, I don’t know.</td>
</tr>
<tr>
<td></td>
<td>“Parents have symptoms”</td>
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<tr>
<td></td>
<td>if you think about genetics, a lot of the parents would have a few of those symptoms if not the whole spectrum so there’s a certain kind of demeanour that goes along with that. They’re pretty fact-focused and to the point. Sometimes pretty blunt about things and that’s got its drawbacks but you know if what I want is the facts, then that’s a strength.</td>
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