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Parental Perceptions of the Diagnostic Process for Autism Spectrum Disorder in British Columbia

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Abstract

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MSc, Brunel University, 2001

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Dissertation Submitted in Partial Fulfillment

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Abstract

In 2014, the Center for Disease Control and Prevention reported that the incidence of autism had reached a prevalence rate of 1 out of every 68 children. This increase means that more families have experienced the difficult Autism Spectrum Disorder (ASD) diagnostic process. Although research on parental perspectives of the ASD diagnostic process is almost 2 decades old, to date, there have been no studies conducted in Canada comparing parental experiences between the private and government-funded assessment routes. Research in general has shown that parents are generally dissatisfied with the ASD diagnosis process. The theoretical foundation for this study is Hochbaum's health belief model that states that variations in a family's health-related decisions are based upon their perceptions of acceptance of the diagnosis, impact of the disorder, benefits and barriers of treatment, and their self-efficacy. The purpose of this correlational study was to examine critically the relationship between parental satisfaction prior to, during, and after the assessment with the type of diagnostic process (government funded or private) that parents chose, as measured by the Parent Perceptions Survey. The study sample consisted of 63 British Columbia parents with children under the age of 6 who were diagnosed with autism. The results of this study indicated that the 3 hypotheses were not supported. The only factor that mattered regarding parental satisfaction of an ASD assessment was the wait time. The implications for social change include practitioner and policy-level recommendations to provide parents a more positive experience when receiving a diagnosis of ASD and to decrease the lengthy ASD assessment waitlists to improve equal access for all families.

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Dedication

This dissertation is dedicated to my supportive husband, Bobby, and my three loving and handsome sons, Govind, Kishan, and Neishhan. Thank you for your encouragement and inspiration throughout this academic journey. To my parents, Ranjit and Balvinder, who always saw this PhD vision with me and helped me reach my academic dream.

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Last but not least, to Babaji, the One above, without you, nothing is possible.

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Chapter 1: Introduction to the Study

The increase in cases of autism in the last few decades has warranted the need for research on this high prevalence disorder. Wing (1998) used the term *Autism Spectrum Disorders (ASD)* to represent the different types of autism disorders, including autistic disorder, Asperger syndrome, and Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS). *The Diagnostic and Statistical Manual of Mental Disorders* (American Psychiatric Association, 2000), defined *autism* as a Pervasive Developmental Disorder (PDD) with marked impairments in social interaction, communication, and restricted repertoire of behaviors, interests, and activities. However, these separate disorders were no longer present in the new *DSM-5* that was released in May of 2013. The *DSM-V* has moved to what it defined as *a single umbrella disorder* because researchers claimed that the four separate disorders, namely autistic disorder, Asperger disorder, childhood disintegrative disorder, and PDD-NOS were not being used consistently in clinical practice (American Psychiatric Association, 2013).

A recent press release report by the Center for Disease Control and Prevention stated that in 2014, the incidence of autism reached a prevalence rate of 1 out of every 68 children compared to previous prevalence rates of 1 in 88. Many ideas about why the rate of ASD is increasing are hypothesized in the literature. These ideas include the notion that that autism is caused by vaccines, pollution, or pesticides (Roberts et al., 2007). Other researchers are firmly convinced that genetics play the largest role in the prevalence rates of ASD (Spence, 2004). However, some researchers have speculated that perhaps ASD is not really increasing in any significant way. The increase may be related to professionals becoming more competent in identifying ASD even in its milder forms due to better diagnostic tools (Hertz-Picciotto & Delwiche, 2009) and to the broad way autism is defined, especially the inclusion of PDD-NOS and Asperger disorder as part of a larger spectrum of conditions.

With this increase in the prevalence of ASDs, families must encounter the difficult diagnostic process and face the challenges of seeking appropriate interventions. To date, there have only been a few studies conducted in Canada examining parental perspectives on the initial ASD diagnosis of their child and how informed they are in seeking appropriate interventions (Siklos & Kerns, 2007). In the geographical region of British Columbia (BC), Canada there are two routes for individuals to obtain a diagnosis of ASD. The first route is the public government funded diagnosis through a network called the BC Autism Assessment Network (BCAAN), which is a network of regionally based diagnostic teams across BC. This process is funded by the Ministry of Health, who has the primary responsibility of providing an assessment and diagnosis of children who may have autism in a timely manner and within a close distance to their homes, especially if they are located rurally (Provincial Health Services Authority, 2012). The second route the families can pursue to obtain a diagnosis of autism is a private diagnostic assessment. Due to the long wait lists for a BCAAN assessment, some parents opt to pay for the diagnosis privately. Private-based diagnosticians still need to abide by the BC Standards and Guidelines (2003) and conduct the mandatory multidisciplinary assessment as required by the Ministry of Children and Family Development (MCFD). According to the ASD working group who compiled the Standards and Guidelines for the

Assessment and Diagnosis of Young Children with Autism Spectrum Disorder in BC (2003), a multidisciplinary assessment is defined as a comprehensive clinical diagnostic process that must include the following: (a) a psychological assessment, (b) a speech and language assessment, and (c) a medical evaluation. In addition, this document further explains that results derived from the diagnostic assessment must also provide for a differential diagnosis, so the ASD diagnosis may require additional assessments such as an occupational therapy assessment, a comprehensive family assessment, a psychiatric assessment, and any other additional speciality assessments that are determined on a case-by-case basis.

Receiving the initial diagnosis of autism can evoke some very difficult emotional challenges for the family. A pertinent study on parent perceptions upon receiving a diagnosis of autism was conducted by Howlin and Moore in 1997 in which they found that parents experience a high degree of stress during the diagnostic process, especially if there is a long delay in receiving the diagnosis. The majority of studies have focused on the disclosure of the diagnosis revealed that most families are dissatisfied in the disclosure of the autism diagnosis for several reasons, including lack of sensitivity on part of the professional, delays in obtaining a diagnosis, and lack of information provided on treatment options to name a few (Brogan & Nussen, 2003; Gasper De Alba & Bodfish, 2011; Smith, Chung, & Vostanis, 1994). A related study conducted by Osborne and Reed in 2008 highlighted some of the key areas related to parent dissatisfaction when receiving an ASD diagnosis. These researchers conducted 15 focus groups across England split into three categories of parents: preschool, primary, and secondary aged children. The common concerns that arose from each group were the following: The diagnostic process should be quicker and easier, the procedure should to be more explicit it its structure and content, there should be better professional training about what ASD is, there should be an increase in the amount of information on ASD the professional possesses, and there should be better knowledge about the treatments for ASD. This study was conducted to extend the research on parent perceptions of the initial autism diagnosis and how much post diagnostic support is offered in the feedback to inform parents about scientifically validated treatments for ASD that appears to be a neglected area of research in the literature (Braiden, Bothwell, & Duffy, 2010), particularly in the geographical region of BC.

Background of the Study

As the prevalence rate of ASD is steadily rising in North America, the frequency of diagnostic assessment also increases. Therefore, if the diagnosing professionals can identify the issues that parents have prior to the diagnosis or during the assessment phase, then they may be more effective and competent in providing the appropriate information and support that families need when they actually receive the devastating diagnosis of autism. According to Braiden et al. (2010), many families express frustration in the diagnostic process, and it is not clear whether their dissatisfaction relates to the diagnosis itself or the entire diagnostic process. Furthermore, although parental perceptions of receiving a mental health diagnosis such as Down Syndrome and Cerebral Palsy has been widely researched in the literature, little research has been conducted in the area of ASD (Braiden et al., 2010). The purpose of this correlational study was to critically examine the relationship between parental satisfaction prior to, during, and after the assessment with the type of diagnostic process (government funded or private) that parents choose.

Greater attention needs to be focused on parental perspectives of the initial diagnosis because these parents could be the driving force behind designing, assessing, and changing the service delivery models within the diagnostic process (Braiden et al., 2010). This study was conducted in BC, Canada to update the research on parental perspectives of the autism diagnosis in a new geographical location. Another characteristic of this study is that it analyzed parental perceptions through two different routes of obtaining an autism diagnosis in BC, namely, the private route and the government-funded route through the BCAAN network.

Problem Statement

Research has shown that families experience emotional distress when receiving a diagnosis of any developmental disability (Poehlman, Clements, Abbeduto, & Farsad, 2005), but significantly high degrees of stress levels amongst parents are seen with parents receiving a diagnosis of ASD (e.g., Blacher & McIntyre, 2006; Schuntermann, 2002). Coupled with this high stress level is the fact that parents may receive insufficient information or misinformation about evidence-based interventions as outlined by the American Academy of Pediatrics and the National Academy of Sciences (Sansosti, Lavik, & Sansosti, 2012). These researchers further argued that parents may perceive the diagnosing professional with uncertainty about the diagnostic process and their child's future prognosis. Equally, due to the ever-changing field of autism, some professionals may be uncertain on what treatments to recommend for ASD. Therefore, more research is needed in the area of parental experiences of the diagnostic process to better help practitioners understand these concerns, provide better information about the disorder, and recommend evidence-based treatment models of service delivery to make the process a more positive experience for these families (Sansosti et al., 2012).

Nature and Purpose of the Study

This purpose of this correlational study was to critically examine the relationship between parental satisfaction prior to, during, and after the assessment with the type of diagnostic process (government funded or private) that parents choose. Of further significance is the need to educate practitioners on the importance of providing a positive and supportive experience for families who are receiving this difficult diagnosis. More research in other geographical regions with various ethnic populations needs to be conducted in this area to update the current literature regarding the specific determinants associated with parental satisfaction of the knowledge and support received at the time of diagnosis to steering them in the right direction when they have to choose the right service provider for their child. This study was designed to address the gap in the literature by examining parent satisfaction levels through two routes of receiving a diagnosis in BC (funded versus private) and how informed they felt about appropriate ASD treatments.

Research Question and Hypotheses

The following research question and hypotheses were developed based on the comprehensive review of the literature on parental experiences of receiving a diagnosis of autism and intervention supports for children with autism. A few key measures were used in this study, and demographic information across BC, Canada was collected. The Manchester Audit Tool originally conducted by Mockett, Khan, and Theodosiou (2011) was modified for this study with consent by the developers to obtain data on parental perceptions of the diagnostic process. In addition, a review of the distribution of the representation of participants using private and public across three demographic factors (age, socioeconomic status, and education level), and an analysis of any differences in proportion of private or public based on age, SES, or education is included in chapter 5 after data were collected.

Research Question (RQ): Is the level of parental satisfaction prior to assessment, during assessment, and after the assessment related to the type of diagnostic process (private versus government)?

$H1_{o}$: There is no significant main effect (private versus government) for overall aggregated satisfaction.

$H1_{a}$: There is a significant main effect (private versus government) for overall aggregated satisfaction.

$H2_{o}$: There is no significant within subjects effect across the three satisfaction scores (before, during, and after).

$H2_{a}$: There is a significant within subjects effect across the three satisfaction scores (before, during, and after).

$H3_{o}$:There is no significant interaction effect for type of diagnostic process with the “satisfaction timing” (before, during, or after).

$H3_{a}$: There is a significant interaction effect for type of diagnostic process with the “satisfaction timing” (before, during, or after).

Independent variables: The type of diagnostic process and private versus government.

Dependent variables: Assessment satisfaction prior, during, and after the assessment.

I attempted to extract other pertinent information from the demographic and Manchester Survey including the degree parents (from the government funded or private routes) are informed and have knowledge of evidence-based treatments after feedback with the psychologist or the multidisciplinary team of diagnosing professionals. Additional analyses were conducted to determine if any demographic variables such income level or education affect a parent’s perceptions of the ASD diagnosis in either route, government funded or private, to obtain an ASD diagnosis. For example, how satisfied an uneducated parent is with the ASD diagnosis and their knowledge of ASD and its treatments compared to an upper class, educated person

Theoretical Base

In order to better understand the parental views on health behavior and health promotion, the health belief model (HBM) originated by Hochbaum (1968) can be applied (Janz & Becker, 1984). The HBM is the theory most commonly used as a schema for explaining health education and health promotion and in predicting an individual’s health-related behavior (National Cancer Institute, 2003). Hochbaum (1958) explained that the HBM model’s underlying concept is that health behavior is determined by one’s personal beliefs and perceptions about the illness and what treatment would most effectively decrease its occurrence. There are some key predictor variables associated with the HBM that include perceived threat, which includes perceived susceptibility and perceived severity as its subcomponents, perceived benefits, perceived barriers, and self-efficacy (Hochbaum, 1958).

The HBM model can be applied to parents with children with autism because according to this model, parents of children with autism have different perceptions and beliefs about their child’s disorder and available treatments. There are numerous decisions to be made when parents are confronted with a diagnosis of autism. According to Wildman (2006), these choices include where a diagnosis should be sought out, what professionals are qualified to diagnose, what diagnostic tests comprise the ASD assessment, and what treatments are best practice for their children. As parents seek to answer these questions, the HBM stated that parents vary on their acceptance levels while trying to make these decisions. These variations in a family’s health-related decision are based upon their perceptions of acceptance of the diagnosis, impact of the disorder, benefits and barriers of treatment, and their self-efficacy (Wildman, 2006). More specifically, when applying the HBM model, the perceived threat refers to the degree of impact this ASD diagnosis entails for their child’s development. Parents also have varying beliefs about the course and outcome of treatment of ASD (perceived benefit) and need to weigh all the negative consequences attached to treatment models including the cost, side effects/dangers, and convenience level involved (perceived barriers). Along the journey of accepting ASD, a parent uses his or her beliefs and self-perceptions to follow through with the procedures necessary to achieve the best outcomes they desire for children (self-efficacy; Wildman, 2006).

Definition of Terms

The following terms will be defined due to the continuous reference to them throughout the study:

Autism Community Training (ACT): ACT is an information and referral service that supports individuals with ASD and their families across BC (ACT, 2013). It also monitors and regulates the service providers who work with children under the age of 6 in BC that include behavior consultants, occupational therapists, speech and language therapists, and physiotherapists.

Applied behavior analysis (ABA): A scientifically validated method of intervention for autism based on the principles of behavior that have been verified by the U.S. National Research Council as clinically effective (Foxx, 2008).

Autism: Often used interchangeably with ASD. Autism is defined as a neurodevelopmental disorder with core deficits in language and communication, socialization, and the existence of unusual repetitive, restricted, and stereotypical interests and behaviors (Carbone, Behl, Azor, & Murphy, 2009).

Autism Spectrum Disorder (ASD): A term used to define autism as a spectrum of neurodevelopmental disorders which encompasses autism, Asperger syndrome, and PDDs (Gasper de Alba & Bodfish, 2011) and is frequently used interchangeably with the term autism.

BC Autism Assessment Network (BCAAN): A program under the Provincial Health Services Authority with a primary role of assessing and diagnosing children who may have autism. Families who go through the government funded diagnosis route will be assessed through BCAAN (National Professional Development Center on Autism Spectrum Disorder [NPDC], 2014).

Evidence-based practices (EBP): The term used to describe scientifically validated treatments for autism. There are rigorous standards that constitute the efficacy of evidence-based interventions using (a) peer-reviewed scientific journals, (b) at least two high quality randomized or quasi-experimental design studies, (c) at least five single subject studies by three different investigators, or (d) a combination of using one high quality randomized or quasi-experimental group design study and three high quality single subject design studies by at least three different researchers (NPDC[, 2014).

Ministry of Children and Family Development (MCFD): A provincial program offering a wide range of programs and services for parents, children, and individuals with special needs. MCFD also provides funding for early intensive intervention programs for autism with a primary responsibility for treatment, training and research, and program evaluation (Standards and Guidelines for the Assessment and Diagnosis of Young Children with Autism Spectrum Disorder in British Columbia, 2003).

Assumptions

In this current study, an assumption was made that parent participation was completely voluntary and that parents were not coerced to participate. It was also assumed that parents were able to understand the survey questions and answered truthfully. The tools selected were assumed to be credible in what they were set out to measure. In addition, an assumption was made that this study would not affect the families' current intervention they have chosen for their child.

Limitations

There are several limitations of this study that need to be considered. First, a convenience sample of parents from various agencies was used; therefore, the sample population may not be truly representative of a larger population of parents with children who are diagnosed with autism. The sample size of the current study was relatively small because it only represented the families in the geographical area of BC, Canada and not extending to other provinces in Canada. Second, responses to the questions on the questionnaires may be biased depending on the variation in the motivation of parents who participated in the study. Similar to Sansosti et al. (2012), the parents who participated in this study may have had very negative experiences with the diagnostic process, so this opportunity allowed them to voice their concerns.

Scope and Delimitations

The scope of this study is limited to the current population of participants selected, which only include parents who have children diagnosed with autism between the ages of 1 and 6 years old who have been diagnosed within the last 3 years in BC, Canada. Parents of children over age 6 were not used in this study in order to closely analyze how informed parents are of early intervention services. Therefore, the results did not reflect any relationships between the diagnosis satisfaction and the quality of post diagnostic support offered for the older child population. In addition, the results of this study should be replicable to other studies that involve examining parent perspectives of the diagnosis experience and seeking interventions specifically for ASD. However, this type of study should not generalize to other disability groups because of the unique symptoms associated with autism and the specific type of treatment needed with this population.

Significance of the Study and Implications for Social Change

One significant aspect of this study is that it addresses several gaps that still exist in the literature. After a careful examination of the literature, one gap that this study addressed is increasing the sample size, relative to previous studies examining parental perceptions of the ASD process (Mockett et al., 2011) and generalizing the results to a different geographical area, which include urban, suburban, and rural areas (Sansosti et al., 2012). This study was quantitative in the hopes of being able to effectively disseminate a large number of questionnaires to a larger population including the more rural communities existing within BC. This rural community could be targeted because the BCAAN network encompasses health care professionals in five geographical regions across BC. Overall, the nature of this study is unique to BC and will hopefully provide support and education regarding early intervention needs to diagnosticians, other medical professionals, and parents with children with autism. This study added to mounting literature on the ASD diagnosis procedure; however, according to Sansosti et al. (2012), only a few studies have assessed parental perspectives during the diagnosis of ASD as this current study examined (Goin-Kochel, Mackintosh, & Myers, 2006; Howlin & Asgharian, 1999).

Furthermore, another gap in the literature that this study addressed is the need to include participants from various ethnic backgrounds. According to Ozonoff and Rogers (2003), even though autism exists equally in all socioeconomic groups, cultures, and ethnic groups, the researchers have not greatly extended their results to include families with ASD from diverse racial and ethnic backgrounds such as African, Latino, Chinese, or South Asian groups. BC is very ethnically diverse, and in this study, I was able to include participants from various ethnic communities such as the predominantly Asian and South Asian populations. Finally, the research has indicated that more work needs to be done in educating health care professionals and diagnosticians in the area of evidence-based interventions for ASD so they can effectively guide these families into the right treatment for their child (Sansosti et al., 2012).

With regards to social change implications, this research should help raise awareness to health professionals and diagnosticians to provide a through explanation of the diagnosis of autism and provide ample information to guide parents regarding their treatment options. This study was conducted in the hope that resulting potential modifications in the diagnostic process may facilitate parents' positive experiences with the diagnostic process so that they feel informed about the diagnosis provided and what treatment options they should seek out for their children. Currently, the number of children being diagnosed is increasing at an alarming rate. Statistics from the Centers for Disease Control and Prevention (CDC) estimated that 1 of 68 children in North America is diagnosed with an autism spectrum disorder (CDC, 2014); therefore, it is important for health professionals to keep up with the current trends of ASD in order to promote positive social change for families receiving this difficult diagnosis. In addition, families using scientifically validated procedures further help children achieve positive outcomes because it will teach them the critical social, language, and play skills needed to reach their optimal level of development. Most importantly, the dissemination of this type of information will decrease the negative experiences parents may have with the diagnostic and post diagnostic process as health professionals will be better able to guide and support these families to effectively navigate the system for ASD in BC, Canada through more in-service training and support.

Summary and Transition

The rapid increase of ASD in North America and globally has prompted the need for increased research in the area of parental satisfaction of the diagnosis process and how this affects the family's choice of treatment for their child. This chapter includes an overview of the two routes of obtaining a diagnosis in BC: studies pertaining to parental perspectives of the diagnostic process and the importance of evidence based interventions for autism. The purpose of this correlational study was to critically examine the relationship between parental satisfaction prior to, during, and after the assessment with the type of diagnostic process (government funded or private) that parents chose.

An examination of these variables allowed me to identify ways for improving the diagnostic process for families. It opened up the recommendation to provide training for health professionals to advocate for evidence-based interventions for ASD treatment. It also added to the growing body of literature on family experiences when receiving a diagnosis (Sansosti et al., 2012).

Chapter 2 will provide a comprehensive literature review on other studies conducted on parental experiences when receiving a diagnosis of ASD, information about the process of diagnosis and its implications in BC, and sources of parental dissatisfaction, of the ASD diagnosis process, and the importance of early intervention for ASD. In chapter 3, I will outline the research methodology, rationale for using the quantitative method, participant selection criteria, sample selection, surveys and questionnaires used. Chapter 4 addresses data analysis and results of the study. Chapter 5 illustrates present conclusions of the study based on the results derived from the measures, limitations of the study, social significance to the field of autism, and future directions for research.

Chapter 2: Literature Review

Introduction to the Disclosure Process

Studies have shown that parents often express feeling unsupported during the autism disclosure, and in turn are not receiving the appropriate services to help their children (Gray, Msall, & Msall, 2008). A literature review on parental perceptions of the diagnostic process for autism is important in order to demonstrate the ongoing need for research regarding the impact of parents' negative experiences during the process and how this can affect post diagnosis support for their child. The current literature only contains a handful of research studies investigating the area of parental satisfaction levels when receiving a diagnosis of autism across over the last 20 years. Disclosure refers to the first time a child's disability is revealed to the family after the formal assessment is complete (Hasnat & Graves, 2000; Nursey, Rohde, & Farmer, 1991). It is an overwhelming and emotionally charged experience that will change the lives of families for a lifetime. Research has shown that the manner in which a child's disability is disclosed can negatively affect the parent's coping and adaptability to the child's disability (Sloper & Turner, 1993). Moreover, a diagnosis can impact the early attachment, interaction, and ongoing treatment of the child (Hasnat & Graves, 2000; Quine & Rutter, 1994).

The many sources of dissatisfaction during a disclosure are similar for parents who receive a diagnosis of ASD and for parents whose children are diagnosed with other disabilities. These similarities regarding parental experiences across both ASD and other childhood disabilities will be discussed and include emotional impact of receiving a diagnosis (Huang, Kellet, & Winesome, 2010), communication of the disclosure (Hasnat & Graves, 2000; Sloper & Turner, 2003), delays in obtaining a diagnosis (Howlin & Moore, 1997; Mandell, Novak, & Zubritsky, 2005; Werner, Dawson, Munson, & Osterling, 2005), complexity of the diagnostic process, including the stress of seeing multiple practitioners (Whitely, Rodgers, & Shattock, 1998), ambiguity of the diagnosis given (Skellern, McDowell, & Schulter, 2005), and lack of information provided for postdiagnostic support (Gasper de Alba & Bodfish, 2011; Howlin & Moore, 1997; Mockett et al., 2012; Rhoades, Scarpa, & Salley, 2007; Silkos & Kerns, 2007). These variables are critical to study in BC because if families are not emotionally supported and educated on autism and its treatment at the stage of initial diagnosis, then they are often left to navigate the complexities of autism and its treatment on their own.

Literature Search

The literature searches were conducted primarily from the EBSCO Host research database at Walden University. Specific databases searched were Academic Search Premier, Mental Measurements Yearbook, A SAGE Full-Text Collection, PsycINFO, PsycARTICLES, PubMed, and Google Scholar. In order to conduct an effective search, the following search terms were used employing the words autism and diagnosis in a variety of combinations: *autism diagnostic process, parental perspectives, parent satisfaction levels, sources of dissatisfaction regarding an ASD diagnosis,* and *diagnostic concerns.*

In the first section of this chapter, the definition of a diagnosis and its purpose is discussed. In the second section, I outline the research regarding parents’ initial perceptions of childhood disabilities in general followed an overview of the issues of diagnosis of ASD specifically in BC. In the third section, I include the sources of dissatisfaction for parents who go through the diagnostic process specifically for ASD. In the fourth section, I examine the research on parental perspectives on the quality of postdiagnostic support families receive at the initial diagnosis. In other words, if the professionals provided enough written and verbal information regarding treatment options that were appropriate for autism. Diagnosticians should discuss the importance of evidence-based treatments for autism in an effort to increase their knowledge of scientifically validated treatments and ultimately seek out appropriate interventions for their child. Families are vulnerable at the time of diagnosis; therefore, a question remains as to what extent families are aware of the therapies that are supported by the research and if they are satisfied with the information provided by the diagnostician at the disclosure session. This knowledge or lack of may ultimately influence their choice of intervention for their child.

Purpose of Assessment and Diagnosis

The purpose of obtaining a diagnosis of ASD is important for several reasons. According to Siegel (1996), a diagnosis is important to identify what is wrong in the child’s development and that a problem has been recognized. A diagnosis helps a family understand their child’s deficits and helps them stop searching for answers to their child’s delays. The second purpose of obtaining a diagnosis is to receive services for treatment. With an ASD diagnosis in particular, Wall (2004) emphasized that the best outcome for parents is to have a label of ASD because of the provision of treatment services that families can access. In addition, according to Perry, Condilac, and Freeman (2002), the four significant reasons why a diagnosis is important are (a) to help understand the individual in order to provide useful information about the person that will help in selecting appropriate interventions, (b) to obtain or clarify an initial diagnosis, (c) to document diagnostic status necessary for access to services or funding, and (d) to obtain information for program evaluation or research purposes (pp. 61-63).

The Process of Diagnosis and Treatment in Canada

In Canada, the process of accessing treatment is fiscally dependent on a diagnosis. The majority of the provinces across Canada offer government funding and intervention programs but the amount of assistance varies by province. In BC in particular, families are not allowed to use treatment services funding by the MCFD until they have a confirmed diagnosis of autism. The United States is one of the only countries where a family can access early intervention prior to receiving a diagnosis of autism.

According to the National Dissemination Center for Children with Disabilities (2013), a federal grant program allows parents to access the Program for Infants and Toddlers with Disabilities (Part C of IDEA), which allows states in operating a comprehensive statewide mandated program of early intervention services for infants and toddlers with disabilities, ages birth through age 3 years, and their families.

A family receives $22,000 a year for a child diagnosed under the age of 6, and $6,000.00 for a child over the age of 6. An organization called ACT took responsibility for regulating some of the service providers for children under 6 years of age operating in BC. In December of 2004, ACT administered the Registry of Autism Service Providers

(RASP) list in conjunction with MCFD. When a professional qualifies on the RASP list, then parents in the under 6 program can purchase their services (ACT, 2013). In addition, according to ACT (2013), the RASP list is updated weekly, and it includes service providers from different professions including behavior analysts who are in charge of implementing and designing evidence-based ABA programs, speech language pathologists, occupational therapists and physiotherapists. There are approximately 190 behavior consultants offering behavioral intervention for children under 6 in BC; therefore, the choices for treatment are vast. In addition, other treatment models not supported by the research also available in BC, but the MCFD funding will not pay for these. These types of interventions include the Relationship Development Index and neurobiofeedback therapy as well as a few other possibilities.

Parental Perceptions of the Diagnosis of Childhood Disabilities

Parental perspectives of the diagnostic process of general childhood disability have been researched for more than 20 years. This research has continuously shown that parent satisfaction as measured through standardized quantitative questionnaires and face-to-face interviews at the time of the diagnosis of a childhood disability is generally low, and more than 50% of mothers who receive a medical diagnosis for their child are dissatisfied with the diagnosis process (Pearson, Simms, Ainsworth, & Hills, 1999; Quine & Pahl, 1987; Sloper & Turner, 1993). Some factors that can influence this satisfaction or dissatisfaction include emotional and negative reactions after the diagnosis, the empathetic nature of the diagnostician, and severity of the disability. These factors are critical to examine in the present study because these are probably similar perceptions experienced by parents receiving a diagnosis of ASD.

Emotional and Negative Reaction After Receiving a Diagnosis

The diagnosis of any disability can be a very emotional and life altering experience for a family. Research has shown that mothers who experience their child diagnosed with a disability are more likely to have clinical depression or depressive symptoms (Bailey, Golden, Roberts, & Ford, 2007). Research has also shown that parents go through the typical grief cycle of loss including shock due to the loss of health expectations, feelings of disempowerment, denial and/or refusal to accept the formal diagnosis, anger towards medical professionals, and fear about the future or not being certain of the level of impairment (Huang et al., 2010). Parents who have unresolved reactions to the initial diagnosis are shown to have insecure attachments to their child, thus resulting in unsupportive care or intervention for the child (Marvin & Pianta, 1996). Therefore, this emotional upheaval families experience at the diagnosis can affect their course of treatment, which can further affect the child’s prognosis. Appropriate interventions for autism are critical for the course of treatment.

Empathetic Nature of the Diagnosing Professional

Professionals and diagnosticians also have an emotionally difficult experience of communicating the results of a diagnosis, especially if the child’s disability is severe (Graungaard & Skov, 2006). Practitioners need to consider parental reaction to the diagnosis as the family’s experience of this initial communication with diagnosticians can have a significant impact on how the family copes with the child’s disability. In a study conducted by Taanila, Syrjala, Kokkonen, and Jarvelin (2002), the difference between high coping families and low coping families was related to five factors: (a) parents' initial experiences with medical professionals, (b) personal characteristics, (c) level of disruption the child's disability has on family life, (d) acting in everyday life, and (e) level of social support. In addition, Therefore, there is a consistent pattern across the majority of studies in the literature examining family views when receiving a diagnosis that show that often these families feel that their needs are unmet. Thus, this study is needed to examine if these views are consistent with how parents receiving a diagnosis of ASD also feel in BC. These initial concerns about a child's new diagnosis can lead to feeling disconnected in the areas of accepting the severity of the child's disability, where to go for intervention, additional financial support, and respite care (Sloper & Turner 1992). The severity of the disability is another variable of disclosure that can impact a family's perception of the diagnostic process. This variable will be examined in the next section.

Severity of the Disability

Another area of disclosure that has been widely studied is the relationship between satisfaction of disclosure and the severity of the disability diagnosed. A study conducted by Sloper and Turner in 1993 found that when a child was diagnosed with a more severe disability, then the parents were satisfied with the disclosure and the professional's sensitivity when the news was delivered. They also reported that if sufficient information was provided to them in the session and they had fair opportunities to ask questions, then satisfaction of the diagnostic process increased. Overall, this study found that 37% of parents were satisfied with the manner in which they received news of their child's disability. Taken together, these studies reinforce the importance of giving parents clear and accurate information and acknowledging their initial questions about their child's developmental concerns (Sloper & Turner, 1993). This issue is an important variable for me to examine because autism is considered a more serious disability' therefore, these parents may perceive a lack of sensitivity from the practitioner that in turn can affect the parent's experience of the diagnosis.

Understanding parental perspectives of receiving a diagnosis of general childhood disabilities help researchers further understand what families going through an ASD diagnosis also experience. There is a significant need to examine what variables influence a parent's perceptions in BC as research within the government funded and private ASD diagnosis is under researched in this topic and in this geographical region.

The Growing Need for ASD Diagnosis in British Columbia

The rate of autism around the world is steadily increasing. In the United States, statistics from the 1980s found the rate of autism to be as low as 0.4 to 0.5 out of every 1000 children. Only 10 years later, the incidence of autism increased to 2 to 6 in 1,000 children diagnosed (CDC, 2007), and then in 2012 the CDC (2012) estimated 1 in 88 children in the United States were diagnosed with autism. The most recent statistics released by The CDC (2013) estimates that 1 in 68 children in the United States are diagnosed with autism. The rising prevalence rates of ASD are equally present in BC, with 1 out of 100 children being diagnosed with autism. As the number of children being diagnosed in BC increases significantly, so does the need for professionals to improve the diagnostic process so it facilitates early detection of autism and appropriate referrals for intervention for these families affected by this lifelong disorder (Rhoades, et al., 2007). In BC, there are only a handful of government funded agencies and private clinics where diagnoses for ASD are made. The rising prevalence rate of autism in this province is making it difficult to meet the immediate demand of early diagnosis. This study is relevant and necessary in BC because it is critical to analyze the variables that may be impacting the quality and efficiency of the diagnostic process for ASD for families.

Research on Parental Perspectives Conducted in British Columbia

The only pertinent study conducted in BC, Canada in relation to this dissertation topic was done by Siklos and Kerns (2006). This was one of the only studies in the literature that focused on the geographical region of BC, Canada. The premise of this study was to examine the hardships that families endure when trying to obtain a diagnosis of ASD for their child. This study is considered a smaller scale study to the Howlin and Moore (1997) study and it looked at the diagnostic experiences of 56 parents of children with ASD and more specifically at the rate of diagnosis in our province. The ages of the children with ASD included in the data collection were under 5 years old who were eligible to participate in behavior intervention programs. These results indicated that on average, children were being diagnosed at about 5 years of age, with boys a bit earlier at 4.5 years and girls at 6 years of age. Over half of the participants were dissatisfied with the process due to receiving such a late diagnosis even though there is increased awareness of autism. Parents were particularly dissatisfied by the initial way the diagnosis was disclosed, and parents expressed that their reactions followed the stages of the grief cycle (e.g., shock, grief, anger, helplessness, and guilt). In addition, not only were these parents dissatisfied with the initial diagnosis, but they expressed frustration with the services they received after the ASD diagnosis as well. In particular, families voiced that they were faced with long wait lists for the critical services their children needed including speech and language therapy, occupational therapy, respite care, and the Ministry funded under 5 Early Intensive Behavioral Intervention Program of BC (Siklos & Kerns, 2006). Many of the research questions posed by Siklos and Kerns (2006) were replicated in the current study to update the status of ASD diagnosis in BC. This present study addressed a gap in the literature on the ASD process by comparing the parental perceptions of parents obtaining a diagnosis via two different routes of diagnosis in BC, namely, the government funded BCAAN network route and the private diagnosis route.

Variables that affect the diagnostic process are crucial to understanding parental experiences when they receive a diagnosis of autism for their child. The next section will focus on the research that has been conducted on parental perspectives of the diagnosis process for ASD and the sources of dissatisfaction expressed by these families when receiving a diagnosis of autism. The next section will provide a more in-depth examination of the sources of dissatisfaction that impact parental perspectives specific to a diagnostic process of autism, including, delays in receiving a diagnosis of ASD, specificity and saliency of ASD, communication of the diagnosis by the diagnostician, limitations of the assessment, and variability of the diagnostic assessment tools, accessibility of the diagnostic site, and socioeconomic status. Consistent with the HBM model, parents experience a *perceived threat*, which refers to the degree of impact this ASD diagnosis subsequently has for their child's development.

Sources of Dissatisfaction

Delays in Receiving a Diagnosis of ASD

One particular variable impacting the diagnostic process is the length of delay between parents first being aware of the symptoms and actually receiving the diagnosis of ASD. Research has shown that the diagnosis process for children being diagnosed with ASD takes considerably longer than the diagnosis of other developmental disabilities, pushing these children into school age (Mandell et al., 2005; Werner et al., 2005). There is evidence that parents have concerns about their children as early as the age of one but an actual diagnosis of autism is not provided until the age of 4 (Chawarska, Klin, Paul, & Volkmar, 2007). The majority of research studies on parental satisfaction on the diagnostic process of ASD often reference one key study in the literature, which was conducted, by Howlin and Moore in 1997. This study highlighted some of the reasons why parents may be dissatisfied when they are receiving diagnosis of autism and many of these factors will be reevaluated in the present study. The Howlin and Moore (1997) study set the tone for future studies to begin exploring the need to examine parental perspectives in the diagnosis of ASD in order to better understand how diagnosticians can improve the way they communicate with families during this sensitive time.

Firstly, delays in receiving a diagnosis were a significant cause of frustration for these families with the average age of diagnosis being 6 years old. Parents reported that they had identified their child's possible autistic features and tendencies as early as 18 months and sought medical help when they were 24 months. Even though these parents recognized the symptoms very early in their child's life, they expressed frustration with how long it took to actually obtain the diagnosis, namely between 3.5 to 6 years of age. These results are consistent with previous studies that parents express more frustration during the diagnosis process and disclosure if they have experienced longer delays in receiving a diagnosis (Howlin & Moore, 1997; Mandell et al.,, 2005; Werner et al., 2005). In addition, a longer delay constitutes multiple referrals across many professionals before a formal diagnosis is made which causes more frustration and dissatisfaction. Research in this area has shown that parents favored the process if they were seen by only a few professionals and if their children were a young age at diagnosis (Goin-Kochel et al., 2006). This late timing of receiving a diagnosis leads to feelings of hostility, confusion, and uncertainty, and avoidance of the child because it in turn leads to slower access to appropriate early intervention services (Wiggins, Daio, & Rice, 2006). The level of dissatisfaction in relation to the lengthy waitlist for an ASD diagnosis was examined in this present study, since currently, the waitlist for a government-funded diagnosis in BC is about 1 year. The length of delay of a diagnosis is also a neglected area of research in BC and this was examined in this current study in order to advocate for changes in the BC health care system.

Communication of the Diagnosis by the Diagnostician

Another source of dissatisfaction is related to how the initial diagnosis by the diagnostician was communicated to the family. Disclosure of the diagnosis is one of the most critical sessions of the diagnostic process and this communication can help form a parent’s level of satisfaction (Hasnat & Graves, 2000). Studies have shown that the way the diagnosis is first presented can strongly influence the way parents cope and adapt to the disorder (Sloper & Turner, 1993). This in turn can further affect how the parents interact with their child and seek treatment (Hasnat & Graves, 2000).

However, there is evidence that the diagnosis disclosure can be a more positive and supportive process if the right systems are in place during that difficult situation. According to Miller and Hanft (1998), the single most important factor in ensuring a positive diagnostic experience is the existence of strong collaborative relationship between parents and professionals. Parental experiences and perspectives of the initial diagnostic assessment impact the initial development of a positive relationship between parents and professionals and any continued ongoing relationship as measured through qualitative interviews with families accompanied by satisfaction questionnaires. These positive perceptions are helpful to explore because the end of goal of this study is identify how social change in the area of diagnostics can make this process more positive for families.

Generally, parents have reported that they are satisfied at disclosure when the following issues are addressed: Firstly, the manner in which the professional disclosed the information. Professionals who were sensitive, knowledgeable, and showed compassion when disclosing the information were more satisfied. Secondly, the amount of information given was an important factor in high satisfaction ratings. Therefore, parents were more satisfied with a significant amount of information than less, no matter how overwhelming. In addition, parents gave more positive ratings if they felt that the professional had acknowledged and accepted their early suspicions of their child's atypical behavior prior to seeing them and if they had the opportunity to ask questions throughout the session (Brogun & Knussen, 2003; Hasnat & Graves, 2000). These results are consistent with Sloper and Turner's (1993) conclusions which states that when the right procedures are in place, then parents experience more satisfaction with the process. In addition, early diagnosis presents many benefits to families and is vital for access to earlier intervention, educational services in school, and family support resources. Families can start researching for support very early in the child's life to promote better long-term gains in the child's cognitive, social, emotional, and academic functioning. This present study examined the professional-client relationship and how satisfied parents were with the way the information about their child's diagnosis is presented.

However, early diagnosis can be confounded by other variables within the diagnostic process that in turn lead to frustration for families. These variables are limitations of the assessment tools which are other sources of dissatisfaction for families.

Diagnostic Tools

Significant diagnostic delays of an ASD diagnosis are the result of a combination of factors. One factor contributing to this delay appears to be related to the quality of early screening and the instruments used. In a study conducted by Sices, Feudtner, McLaughlin, Drotar, and Williams (2003) only 50% of physicians used formal screening instruments and parent questionnaires when assessing for early developmental delays in children compared to other physicians who used informal assessments which were not sensitive enough to detect pick up the autism symptoms early on when parents have initial concerns. Also, research has shown that early autism diagnosis is affected by the lack of early screening instruments (Bryson, Rogers, & Fombonne, 2003).

Secondly, it is this informal assessment procedure that leads to delays in diagnosis because these autism-specific screening instruments are also attributed to the low sensitivity and lack of validation. Some of these specific instruments being used by practitioners are the Checklist for Autism in Toddlers (CHAT), Pervasive Developmental Disorders Screening Test (PDDST), Screening Tool for Autism in Two Year Olds (STAT), Checklist for Autism in Toddlers-23 (CHAT-23), and the Modified Checklist for Autism in Toddlers (M-CHAT; Dumont-Mathieu & Fein, 2005).

Additional delays have been attributed to doctors' low response addressing a parent's concerns due to the inability to adequately assess the etiological symptoms involved in ASD because these symptoms are not overtly obvious (Bryson et al., 2003). This point leads to the next variable that can affect the diagnostic process. Since there are no physical symptoms of autism that can be detected, this leaves the symptoms of the disorder to be quite salient and have a high degree of variability. Therefore, the absence of biological markers makes this disorder challenging to diagnose therefore leading to more frustration amongst families who seek an explanation for their child's delays. This lack of biological symptoms leads to the next variable that affects the diagnostic process for ASD which is the specificity and saliency of the ASD symptoms.

Specificity and Saliency of ASD

This next section will further explain the specificity and saliency of ASD and its symptoms. The existence of other co-morbid disorders that feature similar symptomatology to autism can lead to a misdiagnosis, thus delaying the actual diagnosis which leads to parental dissatisfaction of the entire diagnostic process for ASD. There is so much variability in the nature and development of autism across different children that deriving a diagnosis based on these salient features can become quite difficult, thus leaving parents dissatisfied with the practitioners' feedback regarding their child's initial issues and concerns. Some of these disorders include language delay, Attention Deficit Hyperactivity Disorder (ADHD), Obsessive Compulsive Disorder (OCD), Oppositional Defiant Disorder (ODD) and mental retardation (Cuccaro et al., 1996; Noterdaeme, Amorosa, Milderberger, Sitter, & Minow, 2001; Ohta, Nagai, Hara, & Sasaki, 1987). In addition, up to 58% of diagnosing psychiatrists and pediatricians admitted that had faced diagnostic uncertainty when looking for ASD due to the lack of biological markers that other diseases and disorders may have (Skellern et al., 2005).

Furthermore, parental perceptions regarding an ASD diagnosis can be confounded by other variables, such as the functioning level of the child. Parents whose children are diagnosed with Asperger's versus autism may experience more dissatisfaction in the whole diagnostic process because the symptoms were less obvious, thus the referral for a diagnosis gets delayed. Howlin and Asgharian (1999) found that parents with Asperger disorder experienced significantly more frustration and larger delays when trying to obtain a diagnosis than parents with children with autism. In this study, the mean age of obtaining a diagnosis in the *autism group* was 5.5 years of age and mean age for the *Asperger group* was 11 years old. Research has shown that parents with children with Asperger's expressed dissatisfaction about the feedback they received in the disclosure session in which the diagnostician was more likely to reassure the parents inappropriately that the child will *outgrow* his or her difficulties or that they should not be so worried about their child's symptoms, thus not recommending any intervention services (Howlin & Asgharian, 1999). Parents may be further frustrated when they are given unclear diagnoses such as *autistic tendencies* or *atypical autism*, which in turn leads to further dissatisfaction (Silkos & Kerns, 2007, p.10). This study examined if parental perceptions of the diagnostic procedure are different for families who receive a diagnosis of autism versus Asperger disorder.

Limitations of the Assessment

In addition to the various factors influencing the diagnostic process, limitations of the ASD assessment phase itself also contribute to dissatisfaction. As discussed above, since there is an absence of biological markers in autism to detect its overt symptoms, the assessment of autism can become a very challenging and complex process. As a result, diagnosis relies of the developmental history of the child, clinical judgement, and observations, which becomes a lengthy and draining process for the families (Whitely et al., 1998). This autism diagnosis is based on a multidisciplinary approach with a detailed developmental history based on parent report and putting together multiple reports from multiple practitioners. This lengthy approach was the focus of one of the research questions in this current study, namely, examining the parental perceptions of the multidisciplinary team diagnosis and opinions on the effectiveness of this approach.

Accessibility of the Diagnostic Center

Howlin and Moore (1997) found that geographical area was also a factor in how the whole process was perceived, in that families who were in more isolated regions were less satisfied. A demographic variable that will be examined in this present study is how satisfied are families receiving a diagnosis in rural areas of BC, since typically, these families have to travel to the big city or psychologists are contracted to serve these small communities.

Socioeconomic Status

Another source of dissatisfaction in obtaining a diagnosis of ASD is related to family income level. Families, who have financial resources, typically have more access to obtaining diagnosis for their child. Goin-Kochel et al. (2006) revealed that parents who had a higher education and consequently a higher income, would receive a much earlier diagnosis for their child and this contributed to higher satisfaction with the diagnosis procedure. One of the demographic variables of socioeconomic status and obtaining a private diagnosis in BC will be examined because since BC is the melting pot of Canada, it would be important to examine if families with more financial resources to obtain a diagnosis privately are more or less satisfied with the diagnosis process than families who waited for 1 year on a lengthy waitlist to receive the same diagnosis.

Research on Post diagnosis Support Offered to Families

Researchers have also explored how much awareness and education about autism treatment options are provided so parents can be reassured at the final disclosure meeting (Rhoades et. al, 2007, Sansosti et al., 2012). Diagnosing professionals should have the knowledge to disseminate appropriate intervention for these children after providing a life-altering diagnosis to the families. Research has shown that parents are frustrated about expressed their frustration with the lack of support they received once the diagnosis of autism was provided along with the lack of guidance they received about accessing an adequate educational facility (Gasper de Alba & Bodfish, 2011; Howlin & Moore, 1997; Mockett et al, 2011; Rhoades et al., 2007). More specific factors will also be addressed in the proposed study to answer a critical part of the research questions, which includes: What are the parent perceptions about the amount of or lack of the treatment options given at the diagnosis disclosure? The next section will examine the research conducted in parental dissatisfaction with the actual diagnosis itself and future treatment options.

Parental Perceptions in the ASD Disclosure in Relation to Post Diagnostic Intervention

Research on post diagnosis of ASD has evaluated some factors at the initial ASD diagnosis that have influenced a parent's choice of intervention for their child. Some research in this area has shown that parents reported a disconnect between receiving the diagnosis and obtaining intervention. These parents specifically reported that they did not receive any support after a few months of the diagnosis and were also not aware of the services available to them (Braiden et al., 2010). In the current study, it will be imperative to look at which model, government funded or private, do families have a more positive experience with. Research has shown that some parents expressed dissatisfaction with the information they received prior to and after the diagnosis, and feel that they should be given more information on future interventions for their child

(Mockett et al., 2011). In addition, families reported a lack of guidance on the diagnostician's part regarding the best intervention programs for their child. Therefore, most parents ended up being their own self-advocates and search for interventions (Sansosti et. al, 2011). This elicits a powerful message to professionals that parents should be informed of what services are available to them at the time of diagnosis so they can make informed decisions about their child's intervention. This study examined the level and type of support provided to the parent by the diagnosing professional, and in turn how this impacts their knowledge of seeking the appropriate ASD intervention. Diagnosing professionals need to have this knowledge of effective ASD interventions so they can guide parents in the right direction on early intervention. The next section explains the importance of early intervention for families impacted by a diagnosis of autism.

Importance of Early Intervention

Research over a few decades have shown that the use of evidence-based early intervention can reduce the severity of developmental deficits and delays in autistic children, especially before the age of three (McEachin, Smith, & Lovaas, 1993; Smith, Groen & Wynn, 2000). Several initiatives including the National Research Council (2001) and policy statements made by the American Academy of Pediatrics (2010) and the National Autism Academy (2009) strongly advocate the use of scientifically validated techniques, otherwise referred to as Evidence Based Practices (EBP's) in the diagnosis and treatment of autism. The adoption of these procedures is warranted due to the ever-increasing prevalence rate of ASD. Research shows strong evidence that the most efficacious benefit to scientifically validated early interventions such as Applied Behavior Analysis (ABA) show vast improvements in cognitive and adaptive functioning that can reduce the severity of the autism symptomatology (Dawson et al., 2010). Comprehensive review of the literature has shown that young children at the preschool and elementary school age on diagnosis make significant improvements in their cognitive functioning, language skills, social skills, and adaptive functioning after 1 year in an intensive behavior therapy program (Kabot et al., 2003; Smith, 1999). In addition, after follow-up standardized testing children who received 1:1 intensive ABA therapy 25-40 hours a week for at least 1 year showed up to <20 point IQ gain in their cognitive functioning, and relative increases in language and communication skills, and adaptive functioning than children in control groups who received less intervention, group instruction, or parent-led intervention (Hillman, 2006).

Professionals in the field of autism, diagnosticians included, have an obligation to steer parents in the right direction when it comes to early intervention for autism. Research has shown that the diagnostic process can influence a parent’s search for the right type of intervention. Intensive efforts on the awareness of evidence-based interventions by diagnosing professionals can help enhance the quality of life for these children with this lifelong disorder. This proposed study examined parent perceptions of how informed parents felt they were about post diagnostic support offered to them. This led to a proposed outcome of the study, which involved the need to disseminate current knowledge about ASD and evidence-based intervention options between diagnosing professionals and parents for these children diagnosed with ASD to improve their perceptions of the diagnostic process.

Summary

Chapter 2 included a comprehensive literature review of the research conducted on disclosure process of ASD and the many sources of dissatisfaction experienced by families including delays in receiving a diagnosis of ASD, communication of the diagnosis by the diagnostician, nature of the diagnostic tools, specificity and saliency of ASD, limitations of the assessment, accessibility of obtaining a diagnosis, and socioeconomic status. In addition to these sources of dissatisfaction, this chapter reviewed research of parental perceptions of post diagnostic support and evidence-based interventions for ASD.

Research has illuminated many of the factors that contribute to negative experiences for parents during the emotional diagnosis for autism for their children. Many of these experiences will be examined again to focus on what aspects of the ASD process parents are dissatisfied here in BC, Canada. Very little research has included the BC population where the ASD diagnosis process is very standardized and treatment options are vast. More specifically, it will be important to examine parental experiences of a multidisciplinary assessment, the length of time they waited for an assessment, what demographic variables may influence the accessibility of getting a diagnosis, the diagnostician’s way of communicating the diagnosis, and the amount of support regarding treatment provided at the time of diagnosis. Parental perspectives of the ASD diagnosis is an important variable to examine because this experience may impact the type of treatment a family should be seeking (Howlin & Moore, 1997; Sansosti et al., 2011). As diagnosing professionals it is so critical that we do not create a revolving door paradigm where diagnosis becomes second nature without considering the family's experience. Literature on parental perspectives of the diagnosis process have demonstrated a common theme; in general, families are somewhat dissatisfied about the diagnostic process and this typically leads to some barriers in finding or starting early intervention. Sansosti et al. (2011) explain that diagnosing professionals may not unintentionally understand scientifically validated approaches to autism treatment; therefore parents are left to self-educate themselves on ASD treatment. This lack of information regarding intervention can be a relatively significant source of dissatisfaction to families. Chapter 3 provides a detailed description of the research design and methodology proposed to examine the research question and hypotheses formulated from the problem discussed in chapter 1.

Chapter 3: Research Method

Introduction

In this study, I aimed to improve the understanding of parental perceptions of the diagnostic procedure for autism through two routes of receiving a diagnosis in BC. The first route is the government-funded route through the BCAAN Network and the other is families paying privately to have this diagnosis done at a private practice. The purpose of this correlational study was to critically examine the relationship between parental satisfaction prior to, during, and after the assessment with the type of diagnostic process (government funded or private) that parents choose.

The premise of this study stems from the notion that in order to better help families, it is critical that diagnosticians understand the experiences of parents during the diagnostic process and provide them consistent recommendations for intervention (Sansosti et al., 2011). To date, there has been limited research looking at the diagnostic process associated with receiving a diagnosis of ASD starting from parents sharing their initial concerns to receiving support and intervention (Braiden et al., 2010). Of the studies that have been conducted, the majority of the parents have been dissatisfied with the diagnostic process. In this chapter, I describe the methods used to research the hypotheses of this study, which include a description of the design of the study, instruments used, participants, data collection methods, and data analysis techniques.

Research Design and Approach

The purpose of this correlational study was to critically examine the relationship between parental satisfaction prior to, during, and after the assessment with the type of diagnostic process (government funded or private) that parents choose. A quantitative approach was used by researchers as a means for testing objective theories by examining the relationship amongst them that can be conducted on a large scale (Creswell, 2008). These variables were measured on standardized instruments or tools generating numbered data that can be analyzed using statistical procedures (Creswell, 2008). There are several advantages to quantitative studies. Firstly, quantitative data are statistics driven and can provide information that permits hypothesis testing (Creswell, 2008;Word Press, 2011). There is also an ease when compiling and representing the data on graphs and charts (Word Press, 2011). One of the disadvantages of quantitative research is that it is more costly than using qualitative research (Creswell, 2008; Word Press, 2011). There were no financial costs related to dissemination of the questionnaire.

This study was not experimental in nature as participants were not randomly assigned to specific groups for the purposes of manipulating variables. Rather, scores on a parent experiences survey were assumed to reflect aspects of parental satisfaction of the overall diagnostic process and their perceptions about current interventions that were offered to them at the disclosure meeting. This quantitative approach helps answer the following hypotheses and research question:

RQ1. Is the level of parental satisfaction prior to assessment, during assessment, and after the assessment related to the type of diagnostic process (private versus government)?

$H1_o$: There is no significant main effect (private versus government) for overall aggregated satisfaction.

$H1_{a}$: There is a significant main effect (private versus government) for overall aggregated satisfaction.

$H2_{o}$: There is no significant within subjects effect across the three satisfaction scores (before, during, and after).

$H2_{a}$: There is a significant within subjects effect across the three satisfaction scores (before, during, and after).

$H3_{o}$: There is no significant interaction effect for type of diagnostic process with the “satisfaction timing” (before, during, or after).

$H3_{a}$: There is a significant interaction effect for type of diagnostic process with the “satisfaction timing” (before, during, or after).

Independent variables: The type of diagnostic process, private versus government.

Dependent variables: Assessment satisfaction prior, during and after the assessment.

In addition, a review of the distribution of the representation of participants using private and public across three demographic factors (age, socioeconomic status, and education level), and an analysis of any differences in proportion of private or public based on age, SES, or education is included in chapter 5 after data is collected (e.g., chi square analysis).

Setting and Sample

Participants

The sampling frame selected is inclusion criteria. Salkind (2010) explained that inclusion criteria are a set of predefined characteristics used to identify subjects who will be included in a research study. The participants who were eligible to participate in this study were a convenience sample of parents, using a random sampling approach, whose children were under the age of 6 years old with a diagnosis of autism from a private clinic or through the BCAAN Network received within the last 3 years. The children with autism should have received a diagnosis of ASD under the new *DSM-5* criteria, as all clinicians should be using the new guidelines. However, it should be noted that if clinicians were still using the *DSM-IV* criteria for diagnosis, then the following disorders would be included for eligibility criteria: Asperger disorder, PDD-NOS, Rett's syndrome, and childhood disintegrative disorder. Children with co-occurring disorders with autism such as ADHD were also eligible for this study as long as the primary diagnosis was autism. The random sampling approach was effective for this study because participants from of the ASD population had an equal chance of being selected (Creswell, 2009). For children who have two parents, data were collected from the parent who was identified by the family as primarily responsible for the child's care. For single-parent families, data were collected from the parent who had main custody.

Participants were recruited from various diagnostic clinics, autism organizations, child development centers, and private behavior analysts throughout BC. Attending local parent support group networks and online public autism groups and forums further helped create awareness of this study and helped with recruiting participants. Participants with children under the age of 6 were selected because they were an accessible population in BC as the majority of the ASD assessments are conducted with younger children.

Sample Size Justification

To determine the needed sample size for a 2 X 3 factorial ANOVA, the G*Power 3.1 software program (Faul, Erdfelder, Buchner, & Lang, 2009) was used. Based on a medium effect size ($f^2 = .15$), an alpha level of $\alpha = .05$, the needed sample size to achieve sufficient power (.80) should have been 74 respondents. One of the primary benefits of using a repeated measures ANOVA test is that fewer respondents are needed because the researcher can remove between-subject differences out of the error term, making the test more sensitive to reject the null hypothesis.

Procedures

Participants were selected based upon the participant eligibility criteria. A consent form inviting participation and explaining informed consent were sent to each potential family, indicating the purpose of the study as well as participation details (Appendix C). Confidentiality of all families were preserved by assigning each participant initials on their paperwork once consent forms were signed. Once this was complete, families were able to access the survey, the Parent Perceptions Survey, online through an email link. Families who did not have access to the Internet or did not feel competent filling them out this way had the option of completing the questionnaire paper and pencil style. Participants who consented to participate through the email link had access and completed all the forms at once. The questionnaires took approximately 20 to 30 minutes to complete and should not have presented any major constraints other than time.

Once data collection was completed, the data analysis was conducted using statistical software called SPSS. All families received thank you emails from me thanking them for participating in the study.

Data Collection and Analysis

Data Analysis

The design for this study used only one administration of the survey. Satisfaction with the process “before the assessment” was measured in survey items 1through 5. Satisfaction with the process “during the assessment” was measured in survey items 6 through 15. Satisfaction with the process “after the assessment” was measured with survey items 16 through 28.

For the research question, a 2 X 3 factorial ANOVA was used in addition to three *t* tests for independent means. A 2 X 3 factorial ANOVA was used where the independent variable was the type of diagnostic process (private versus government) and the within-subjects (repeated measures) variables were the timing of the satisfaction ratings (before, during, and after the assessment process). In addition, point biserial correlations were calculated to determine the strength of relationship between the type of diagnostic process and each of the three satisfaction ratings. Data analysis was conducted using SPSS 20.0.

Instrumentation and Materials

Demographics

A demographic questionnaire was used to gather information from participants regarding parent and child characteristics that may be confounding variables in the study. Parent and child age, gender, ethnicity, level of education, and socioeconomic status were collected. Information regarding the child’s diagnosis, age of diagnosis, other diagnoses, and what system the parent used to access a diagnosis (private versus government funded) were also collected. Families with more than one parent in the home were identified as to which of the parents was to be considered the primary parent for the purpose of the study.

Manchester Audit Tool Survey

Permission was granted by the author use the revised Manchester Audit Tool developed by Mockett et al. (2011; see Appendix D) for this study. This tool was originally used by Mockett et al. and was published in a peer-reviewed journal to assess parental satisfaction in the diagnosis of their children with ASD in Manchester, England with an attempt to improve the multidisciplinary approach by the Manchester Child and Adolescent Mental Health Service. The population that the instrument was previously used with consisted of parents of 35 children diagnosed with ASD from December 2008 to May 2010 who were invited to participate in this study via mail, telephone, or face-to-face to complete the questions on the survey.

This tool was changed to make it applicable to the Canadian system of receiving a diagnosis of ASD (see Appendix B). In addition, some items were changed to reflect the Likert scale in order to keep it purely quantitative. The Likert-type scale response anchors that were appropriate for the questions on the survey were chosen as a level of agreement on a 5-point scale as follows: (1) *strongly disagree*, (2) *disagree*, (3) *neither agree or disagree*, (4) *moderately agree*, and (5) *strongly agree* (Vagias, 2006). Satisfaction was measured in three different areas of the assessment process: (a) before the assessment, (b) during the assessment, and (c) outcome of the assessment. This study contributed to the current research conducted using this instrument and its usefulness in quantifying specific aspects of parental satisfaction of the ASD diagnostic process.

Pilot Study

In order to establish reliability and validity, a pilot study was conducted where 10 volunteer respondents who had similar characteristics to the target population were recruited to complete the survey. Along with completing the survey, they were queried about any parts of the survey that they did not understand.

The three sets of items for the study, before (Survey Items 1 to 5), during (Survey Items 6 to 15), after (Survey Items 16 to 28) were examined using Cronbach alpha reliability coefficients to assess the survey's internal reliability. Content validity of the study was determined by giving the survey to three experts in this field. Their comments/revisions did not need to be included because all three expert reviewers rated all the questions to be appropriate for this study and did not need to be changed or reworded in any way.

Reliability and Validity

In order for a study to be reliable, it should also be valid. Reliability is the extent to which a study yields the same result on repeated trials of the constructed instrument and validity refers to the degree to which a study measures what the researcher set out to measure (Creswell, 2009).

Ensuring Reliability

Reliability was established through internal consistency, which is the extent to which tests assess the quality and precision of the measuring instrument used in the study

(Creswell, 2009). In this study, the Manchester Audit Tool was used to identify the participant's level of satisfaction on the ASD diagnosis process. Analyzing the internal consistency of the survey items looking at satisfaction revealed the extent to which the items on the questionnaire focus on the notion of satisfaction (Howell et al., 2012). This was calculated using the Cronbach's alpha, which is the most common measure of internal consistency or reliability, and is mainly used for research that incorporates multiple Likert questions in a questionnaire format (Laerd Statistics, 2013).

Ensuring Validity

Validity of this study was be established by obtaining face validity. According to Howell et al. (2012), face validity is defined as how a measure or procedure appears to be assessing the intended construct under study. It attempts to identify how well the questionnaire is designed and whether it appears to represent a reasonable way to gain the information the researchers are attempting to obtain. Face validity was obtained by distributing the questionnaire to a few experts in the field and having them review the questionnaire and provide feedback on whether it measures what it intends to measure.

Threats to Validity

Threats to External Validity

This study was not experimental in nature, there were no uncontrolled extraneous variables affecting parental responses on the questionnaires. The only foreseen threat to external validity would be if the sample was not representative of the ASD population (Creswell, 2009), or generalizable to parents at large who have children with ASD. This depended on the number of questionnaires filled out by willing participants.

Threats to Internal Validity

Since this study was not experimental and did not involve the manipulation of an independent variable to examine its effect on one or more dependent variables; therefore no causal inferences will be provided (Creswell, 2009). The only threat to validity that needs to be addressed is one of instrumentation. Since there is no standardized tool to assess parental satisfaction for the ASD diagnostic process, a modified tool developed by previous researchers for their particular study was used (Mockett et al., 2012). This tool has not been used widely across studies; therefore its validity may not be well established.

Protection of Human Participants

Many ethical precautions were taken to ensure the maximum protection and confidentiality of the participants after IRB approval. Firstly, all participants received consent forms thoroughly explaining study procedures, participant requirements, confidentiality, the voluntary nature of the study, potential risks and benefits of participation, and contact information for the researcher and chair person if they have questions regarding any phase of the study. Participants were also notified in writing of their right that they can withdraw from the study at any time. Secondly, explanations were provided on the consent form regarding any potential risks and benefits. There were no major anticipated physical or emotional risks or benefits when filling out the questionnaires other than the participants possibly feeling some mild stress because they are recollecting a difficult past event. There is a possibility that the parent could experience some upset or frustrations when completing the questionnaires because it requires them to go back and reflect on the diagnostic experience and the disclosure of ASD. With this possibility that participants can encounter emotional distress, the researcher provided a written explanation on the consent form prior to the participant starting the study that they do not have to complete those elements of the survey tools or may withdraw from the study at any time. All questionnaires are strictly confidential and just parent initials were used on the actual protocols. The parent name and child information only appeared on the signed consent forms and only the researcher had access to them.

All the data collected from Question Pro are being kept on a password-protected flash drive. Hard copies filled out by participants are kept in a locked filing cabinet. The data will be destroyed after 7 years.

Summary

The research design and rationale described in this chapter indicates justification for utilizing a quantitative approach in order to most effectively gather satisfaction scores, through independent t tests related to the research question within a random population of parents with children with ASD. The questionnaire that was developed by Mockett et al., (2011) will help the reader understand the parental perspectives of the entire diagnostic process from the prediagnostic phase, to the actual assessment and diagnosis of the child, to the post diagnosis or follow-up phase. Past and current research has typically shown that the majority of parents are dissatisfied with the ASD diagnosis procedure, professional’s role within the assessment, and the lack of post diagnostic information on treatment offered to families (Gasper De Alba & Bodfish, 2011; Sansosti et al., 2012).

Findings from this study may help raise awareness to professionals and diagnosticians in BC about the experiences parent's go through as their child is being diagnosed with ASD. These experiences include how informed parents were about what the diagnostic process entails, how the parents felt they were treated by the diagnostician, how well did they understand the results at the feedback session, and how much verbal and written information on intervention for ASD was provided to them. This information may provide some direction for changes that may need to be implemented throughout the ASD process including a handbook outlining the process at the initial parent interview, and at the feedback session, a diagnostic summary sheet, brochures on scientifically validated interventions, and step-by-step instructions on how to access funding and set up an ABA program handed to parents. This information would help parents understand the process better, thus possibly increasing more positive experiences for the families.

Confidentiality of the participants and ethical concerns are addressed in this chapter. Data collection and analysis, along with issues of reliability and validity were also discussed and delineated. Chapter 4 will present the findings of the study including descriptive and inferential statistical analysis proposed hypotheses.

Chapter 4: Results

In this chapter, the results of the study will be discussed and interpretations and analysis of the data provided. The purpose of this correlational study was to critically examine the relationship between parental satisfaction before, during, and after a child's assessment of autism for each type of diagnostic process, namely, government funded or private that parents chose. Sixty-three surveys of the 74 needed as per the power analysis were completed in a 2-month timeframe. Data analysis was conducted using SPSS 20.0. In this chapter, I describe the sample of participants and provide an overview of the pilot study, design, and procedures, and summarize the results of the analysis.

Pilot Study

In this next section, I will discuss the pilot study and the results that were needed to launch the study. A pilot study was conducted to establish reliability and validity of the Manchester Audit Tool as it was modified in order to make it applicable to administer to families with children with ASD in BC. There were two components of the pilot study to complete. The first part was to establish content validity of the modified tool, and the second part was to establish reliability by selecting 10 participants who were not involved in the final study.

To establish content validity, three experts certified in ASD assessments were queried as to whether the 28 survey items were suitable and valid for this study. They were also asked to make suggestions on how to improve the wording. The background credentials of the three experts were as follows: Expert #1 (20 years of professional experience, PhD, registered psychologist, Clinical Psychology), Expert #2 (4 years of professional experience, Doctor in Psychology, PsyD), and Expert #3 (2 years of professional experience, MEd. School Psychology). All three experts reviewed the 28 survey items and rated all 28 to be appropriate for this study and did not need to be changed or reworded in any way.

A pilot study was then performed using survey data from 10 respondents who met the eligibility criteria for the study. For the three scales, the Cronbach alpha reliability coefficients were as follows: satisfaction before testing ($\alpha = .71$), satisfaction during testing ($\alpha = .83$), and satisfaction after testing ($\alpha = .80$). These findings suggested all three scales had acceptable levels of internal reliability (Creswell, 2007

Demographics Characteristics of the Sample

In this section, I will describe the demographic characteristics of the sample and the respective tables. All eligible participants completed two surveys during a designated 3-month time frame. Eligibility requirements were parents or legal guardians with children under the age of 6 diagnosed with autism within the last 3 years. In total, 63 participants were recruited through various autism agencies and support group networks in BC.

Table 1 displays the frequency counts for selected variables. There were (54.0%) government funded assessments and (46.0%) private assessments. The most common respondents were mothers (76.2%) followed by fathers (17.5%). The ages of the respondents ranged from 22 to 60 years old (*M* = 35.13, *SD* = 6.23). Most respondents (69.8%) were married. The most common racial or ethnic groups for the respondents were Caucasian (60.3%) and Indo Canadian (20.6%). The highest level of education ranged from partial junior high school (1.6%) to graduate degree (33.3%) with 60.3% having earned at least a college degree. Household income ranged from under \$20,000 (12.7%) to \$120,000 and above (6.4%) with the median income being \$70,000. The child being assessed ranged in age from 13 to 144 months (M = 54.14, SD = 26.98). There were almost three times as many male children (73.0%) as female children (27.0%). The child's education level was either none or preschool (74.6%) or kindergarten (25.4%). Almost all (96.8%) had a diagnosis of ASD. The number of months of waiting before the child was assessed ranged from 0 to 18 months (M = 7.15, SD = 4.52; see Table 1).

Table 1

Frequency Counts for Selected Variables (N = 63)

Variable	Category	*n*	*P*
Type of diagnostic process			
	Government funded	34	54.0
	Private	29	46.0
Relation to child			
	Mother	48	76.2
	Father	11	17.5
	Other	4	6.3
Age [a]			
	22–30	13	20.6
	31–34	18	28.6
	35–39	16	25.4
	40–60	16	25.5
Marital status			
	Married	44	69.8
	Single	5	7.9
	Divorced	7	11.1
	Common law	7	11.1

(Table 1 *continues*)

Table 1 *Continued*

Variable	Category	*n*	*P*
Race/ethnicity			
	Caucasian	38	60.3
	Asian	6	9.5
	Indo Canadian	13	20.6
	Muslim	3	4.8
	European	2	3.2
	Black	1	1.6
Highest education			
	Partial junior high school	1	1.6
	Partial high school	4	6.3
	High school graduate	11	17.5
	Partial college training	9	14.3
	College graduate	9	14.3
	Partial graduate or professional training	8	12.7
	Graduate degree	21	33.3
Household income [b]			
	Under $20,000	8	12.7
	$20–$39,000	14	22.2
	$40–$59,000	9	14.3
	$60–$79,000	11	17.5
	$80–$99,000	4	6.3
	$100–$119,000	13	20.6
	$120,000 and above	4	6.4
Child's age in months [c]			
	13 to 23 months	6	9.5
	24 to 35 months	10	15.9
	36 to 59 months	22	34.9
	60 to 83 months	17	27.0
	84 to 144 months	8	12.7
Child gender			
	Male	46	73.0
	Female	17	27.0

Table 1 *Continued*

Table 1 *Continued*

Variable	Category	*n*	*P*
Child's education			
	None or preschool	47	74.6
	Kindergarten	16	25.4
Current diagnosis			
	Autism spectrum disorder	61	96.8
	Asperger's disorder	1	1.6
	Pervasive developmental disorder	1	1.6
Months of wait time [d]			
	0–4	19	30.1
	5–8	23	36.5
	9–12	16	25.5
	13–18	5	7.9

Note. [a] *M* = 35.13, *SD* = 6.23 . [b] Income: *Mdn* = $70,000. [c] *M* = 54.14, *SD* = 26.98 [d] *M* = 7.15, *SD* = 4.52.

Table 2 displays the frequency counts for comorbidity or secondary diagnoses that the children of the participants might also have. It should be noted that respondents could endorse more than one answer that would indicate if they have any comorbid conditions with the ASD. Forty-eight percent of participants reported that the child had no secondary or comorbid conditions. The most commonly reported conditions were sensory processing (13.0%), anxiety (13.0%), ADHD (10.0%), and digestive impairment (10.0%; see Table 2).

Table 2

Frequency Counts for Comorbidity or Secondary Diagnosis Sorted by Highest Frequency (N = 63)

Diagnosis	*n*	*P*
None	30	48.0
Other	14	22.0
Sensory processing	8	13.0
Anxiety	8	13.0
ADHD	6	10.0
Digestive impairment	6	10.0
Depression	5	8.0
Hearing	3	5.0
Seizures	2	3.0
Obsessions	2	3.0
Mental retardation	2	3.0
Dietary issues	1	2.0
Medical	0	0.0
Vision	0	0.0
Schizophrenia	0	0.0

Note. Multiple responses were allowed.

Table 3 displays the statistics (means, standard deviations, lows, highs, and Cronbach alpha coefficients) for the three satisfaction with assessment scale scores: before, during, and after. These ratings were based on a 5-point metric: 1 = *Strongly Disagree* to 5 = *Strongly Agree*. All three Cronbach alpha reliability coefficients were greater than $\alpha > .70$ suggesting acceptable levels of internal reliability (Creswell, 2007) (see Table 3).

Table 3

Psychometric Characteristics for the Satisfaction Before, During, and After Assessment Scale Scores (N = 63)

Score	Number of items	*M*	*SD*	Low	High	α
Satisfaction before	3	3.29	0.94	1.00	5.00	.74
Satisfaction during	10	3.40	0.66	1.90	4.50	.83
Satisfaction after	11	3.21	0.66	1.91	4.70	.81

Note. Ratings were based on a 5-point scale: 1 = *Strongly Disagree* to 5 = *Strongly Agree*.

In this study, a total of 57 tests of significance were performed: Table 4 (44 separate tests), Table 5 (six tests), Table 6 (three tests), Table 7 (two tests), Table 8 (one test), and Table 9 (one test). Using the Bonferroni adjustment, only findings that were significant at the $p < .001$ level would be considered to be statistically significant. As a general approach to reporting statistical significance, in this chapter, I will only report the Bonferroni adjusted probabilities to minimize the possibility of family-wise Type I errors.

Table 4 displays the Spearman rank-ordered correlations between 11 demographic variables and the three satisfaction scores (before, during, and after) as well as the type of assessment process (government versus private). Spearman rank ordered correlations were used instead of the most commonly used Pearson product-moment correlations due to the use of a small sample size in this study ($N = 63$; Gravetter & Wallnau, 2009). Another reason to select nonparametric correlations was that two of the demographic variables (education and income) were measured on the ordinal level. For the resulting 44 correlations, there were 11 significant at the $p < .\ 001$ level. Specifically, satisfaction during the assessment was higher with fewer months of wait time before the assessment began (r_s = -.49, $p < .001$). Satisfaction after the assessment was higher with fewer months of wait time before the assessment began (r_s = -.45, $p < .001$). Respondents who had a private assessment had fewer months of wait time before the assessment began (r_s = -.58, $p < .001$; see Table 4). Based on the Bonferroni adjusted level of significance ($p < .001$), three measures were related to wait time: satisfaction during assessment, satisfaction after the assessment, and type of process.

Table 4.

Spearman Correlations Between Selected Variables and Measures of Satisfaction Before, During and After the Assessment of ASD Testing and Diagnosis Location (N = 63)

Variable	Before	During	After	Type of process [a]
Age	-.01	-.06	.01	.27
Married [b]	-.15	-.18	-.06	.12
Caucasian [b]	.06	.16	-.02	-.03
Highest education	-.08	.13	-.07	.08
Household income	-.05	.06	.27	.42
Child’s age in months	-.30	-.17	-.01	-.14
Child gender [c]	-.10	.00	-.07	-.27
Child's education	-.07	-.08	.01	-.03
Type of process [a]	.27	.15	.23	1.00
Months of wait time	-.41	-.49 ****	-.45 ****	-.58 ****
Age at diagnosis	-.27	-.15	-.08	-.01

Note. Only those correlations that were significant at the $p < .001$ level are annotated as significant to minimize the likelihood of a Type I error.
* $p < .05$. ** $p < .01$. *** $p < .005$. **** $p < .001$.
[a] Type: 1 = *Government* 2 = *Private*.
[b] Coding: 0 = *No* 1 = *Yes*. [c] Gender: 1 = *Male* 2 = *Female*
.

Table 5 displays the *t* test comparisons for selected variables between the government and private assessment process. The parent’s age (mean parent age for government and private), the child’s age in months and the respondent’s level of satisfaction during the assessment did not differ significantly between those who underwent government and private assessments. However, private-assessment families (*M* = 4.41) had a significantly shorter wait time than the government-assessment families (*M* = 9.49). Using the Bonferroni probability adjustment ($p < .001$), only the *t* test for wait time would still be considered to be statistically significant (see Table 5).

Table 5

t-Test Comparisons for Selected Variables Based on Type of Assessment Process (N = 63)

Variable	Type	*n*	*M*	*SD*	η	*t*	*P*
Parent's age					.16	1.28	.21
	Government	34	34.21	6.55			
	Private	29	36.21	5.75			
Child's age in months					.10	0.75	.46
	Government	34	56.49	25.98			
	Private	29	51.38	28.31			
Months of wait time					.56	5.33	.001
	Government	34	9.49	4.03			
	Private	29	4.41	3.43			

Answering the Research Question

The primary research question for this study asked, “Is the level of parental satisfaction before assessment, during assessment, and after the assessment related to the type of diagnostic process (private versus government)?” This question had three related hypotheses.

Hypothesis 1 predicted that "*H*1a: There is a significant main effect (private versus government) for overall aggregated satisfaction." To test this, a repeated measures ANOVA of satisfaction scores) across the three assessment times (before, during and after) was conducted (see Table 6). The main effect for the type of assessment process (government versus private) was not significant ($p = .08$) with government ($M = 3.17$, $SE = 0.11$) versus private ($M = 3.45$, $SE = 0.12$). Based on the above statistical test, the null hypothesis is not rejected, and the finding would not be interpreted as supporting the alternative hypothesis.

Hypothesis 2 predicted that "*H*2a: There is a significant within subjects effect across the three satisfaction scores (before, during, and after)." To test this, a suitable repeated measures model was created (see Table 6). The within subjects effect was not significant ($p = .16$). Based on the above statistical test, the null hypothesis is not rejected, and the finding would not be interpreted as supporting the alternative hypothesis.

Hypothesis 3 predicted that "*H*3a: There is a significant interaction effect for type of diagnostic process with the "satisfaction timing" (before, during, or after)." To test this, a suitable repeated measures model was created (see Table 6). The interaction effect was not significant ($p = .16$). Based on the above statistical test, the null hypothesis is not rejected, and the finding would not be interpreted as supporting the alternative hypothesis.

Table 6

Repeated Measures ANOVA for Satisfaction Based on Diagnosis Location (N = 63)

Source	*SS*	*df*	*MS*	*F*	*p*
Type of process [a]	3.75	1	3.75	3.23	.08
Time	1.00	2	0.50	1.88	.16
Time X type	0.99	2	0.50	1.86	.16
Error (type)	70.82	61	1.16		
Error (time)	32.47	122	0.27		

Note. [a] Type: Government ($M = 3.17$, $SE = 0.11$) versus Private ($M = 3.45$, $SE = 0.12$).

Table 7

t Test Comparisons for Selected Variables Based on Type of Assessment Process (N = 63)

Variable	Type	*n*	*M*	*SD*	η	*t*	*P*
Satisfaction before					.24	1.94	.06
	Government	34	3.08	0.88			
	Private	29	3.53	0.95			
Satisfaction during					.07	0.58	.57
	Government	34	3.36	0.60			
	Private	29	3.45	0.72			
Satisfaction after					.23	1.84	.07
	Government	34	3.07	0.66			
	Private	29	3.38	0.63			

Additional Findings

Additional *t* tests (see Table 7) compared the respondent's level of satisfaction before, during, and after the assessment process between the government and private ASD diagnostic process. None of the three *t* tests were significant at the $p < .05$ level (see

Table 7).

As an additional set of exploratory analyses, Tables 8 through 10 displays the results of the stepwise regression models predicting satisfaction before (see Table 8), during (see Table 9), and after (see Table 10) the assessment using the 11 independent variables from Table 4 as candidate variables.

In Table 8, a 2-variable model (months of wait time and age of diagnosis) was found to predict satisfaction before the assessment. This model was significant (p = .001) and accounted for 23.5% of the variance in reported level of satisfaction. Inspection of the table found a significant proportion of explained variance of satisfaction scores for weight time (β = -.42, p = .001) and age of child at diagnosis (β = -.26, p = .03). Using the Bonferroni probability adjustment (p < .001), only the wait time beta weight would still be considered to be statistically significant (see Table 8).

Table 8

Prediction of Satisfaction Before Diagnosis Based on Selected Variables. Stepwise Multiple Regression (N = 63)

Variable	*B*	*SE*	β	*p*
Intercept	4.41	0.30		.001
Months of wait time	-0.09	0.02	-.42	.001
Age at diagnosis	-0.01	0.01	-.26	.03

Note. Final model: F (2, 60) = 9.21, p = .001. R^2 = .235. Candidate variables = 11.

In Tables 9 and 10, 1-variable models were found to predict satisfaction during the assessment. This model was significant (p = .002) and accounted for 14.4% of the variance in the dependent variable. Inspection of the table found satisfaction during the assessment to be higher for respondents who had shorter wait times to be assessed (β = -.38, *p* = .002; see Table 9). However, this finding was not considered to be significant using the Bonferroni corrected standard of *p* < .001.

Table 9

Prediction of Satisfaction During Diagnosis Based on Selected Variables. Stepwise Multiple Regression (N = 63)

Variable	*B*	*SE*	β	*p*
Intercept	3.79	0.15		.001
Months of wait time	-0.06	0.02	-.38	.002

Note. Final model: *F* (1, 61) = 10.23, *p* = .002. R^2 = .144. Candidate variables = 11.

In Table 10, a 1-variable model was found to predict satisfaction after the assessment. This model was significant (*p* = .001) and accounted for 19.8% of the variance in the dependent variable. Inspection of the table found satisfaction after the assessment to be higher for respondents who had shorter wait times to be assessed (β = -.45, *p* = .001; see Table 10).

Table 10

Prediction of Satisfaction After Diagnosis Based on Selected Variables. Stepwise Multiple Regression (N = 63)

Variable	*B*	*SE*	β	*p*
Intercept	3.68	0.14		.001
Months of wait time	-0.07	0.02	-.45	.001

Note. Final model: *F* (1, 61) = 15.09, *p* = .001. R^2 = .198. Candidate variables = 11

Summary

In summary, this study included surveys for 63 respondents to examine critically the relationship between parental satisfaction before, during, and after an assessment of ASD and the type of diagnostic process (government funded or private) that parents chose. The results of this study indicated that the three hypotheses were not supported, but that the only factor that mattered to families pertaining to satisfaction of an ASD assessment was the wait time to get into an assessment. Although there was no overall difference in mean satisfaction scores between government and private assessment (Hypothesis 1), no overall change in satisfaction scores during the course of the assessment process (before, during, and after assessment (Hypothesis 2) and no significant interaction effect for the type of diagnostic process with the "satisfaction timing" namely, before, during, and after (Hypothesis 3), there were some significant correlations between some demographic variables and satisfaction scores. The most consistent finding was the correlation-between assessment satisfaction and the length of time the family had to wait to be assessed with families who had shorter wait times being more satisfied (see Tables 4 and 8 through 10). In chapter 5, these findings will be compared to the literature, conclusions, and implications will be drawn, and a series of recommendations will be suggested.

Chapter 5: Discussions, Conclusions, and Recommendations

This chapter is organized in seven sections. In the first section, I provide a brief overview of why and how the study was conducted and a review of the research question. The second section addresses the interpretation of findings in the context of the peer reviewed literature and the proposed theoretical framework. The third section shows the limitations and generalizability of the study's overall results and additional findings. The fourth section indicates conclusions and implications of the study, including humanitarian implications. The fifth section addresses recommendations for action, and the sixth section involves the implications for social change including pertinent practitioner and policy recommendations. In the final section, I discuss recommendations for future research that include some methodological enhancements and expanding the research. I end the chapter with a brief summary of the overall study and final conclusions.

Overview of the Study

The purpose of this nonexperimental quantitative study was to critically examine the relationship between parental satisfaction prior to, during, and after the assessment with the type of diagnostic process (government funded or private) that parents choose. I attempted to answer one pertinent research question: Is the level of parental satisfaction prior to assessment, during assessment, and after the assessment related to the type of diagnostic process (private versus government)? In addition, a review of the distribution of the representation of participants using private and public across three demographic factors (age, socioeconomic status, and education level), and an analysis of any differences in proportion of private or public based on age, SES, or education is analyzed.

In this study, I attempted to address several gaps that still exist in the literature pertaining to examining parental perspectives during the diagnosis of ASD. Firstly, I increased the sample size and generalized the results to a new geographical area with an inclusion of the urban, suburban, and rural areas as argued by Sansosti et al. (2012) in their research study. This is study is one of the first to be conducted in BC, Canada. A second gap this study addressed was the inclusion of participants from various ethnic backgrounds. According to Ozonoff and Rogers (2003), even though autism exists equally in all socioeconomic groups, cultures, and ethnic groups, prior research did not extend their results to including families with ASD from diverse racial and ethnic backgrounds. Since BC is very ethnically diverse and considered the melting pot of Canada, greater access to participants from various ethnic communities such as the Asian and South Asian populations was available. Yet another gap that this study addressed was comparing parental perceptions across two different assessment routes (private versus government), which has not been compared in any other study. To summarize, this current study added to the dearth of literature on the ASD diagnosis procedure that is an understudied topic in the ASD literature (Goin-Kochel et al., 2006; Howlin & Asgharian, 1999; Sansosti et al., 2012). In the next section, I will discuss the interpretations of the findings for this study and explain their clinical significance.

Interpretation of the Findings

In this section, I will discuss the most significant findings from the present study and provide interpretations of those results. The primary research question for this study asked the following: Is the level of parental satisfaction before assessment, during assessment, and after the assessment related to the type of diagnostic process (private versus government)? This question had three related hypotheses. These findings provided no support for the alternative hypotheses and therefore provided support to retain all three null hypotheses.

The most significant correlation found with regards to assessment satisfaction was the length of time the family had to wait for their child to receive an ASD assessment. It did not matter which route (government or private) the parents chose; they just wanted the diagnosis done with the shortest wait possible. This present study showed that the average wait time in BC ranged from 0 months to 18 months, with the government funded assessment wait time to be the longest. However, more research is needed to confirm these findings because this population may be not be representative of the population of families with children with ASD in BC. The sample size was quite small, with only 63 families recruited to participate.

Interpretation of Additional Findings

A more detailed analysis of the demographic variables in relation to the assessment process indicated the following conclusions at the $p < .05$ level the before the Bonferroni statistical calculation was done. Due to the exploratory nature of this study and the significance of these results to the ASD population in BC, these results are important to discuss. Some important findings were found when I looked at parent satisfaction scores at different times throughout the ASD assessment, namely, before, during, and after the assessment. These questions were on the Parent Perceptions Questionnaire, which was the tool used in this study (see Appendix B).

The questions on the survey pertaining to "before the assessment" examined how informed parents felt prior to the assessment phase starting, such as knowing what the ASD diagnostic process would entail from beginning to end and the professional's name and credentials before seeing them. Specifically, satisfaction before the assessment was higher (a) when the child was younger ($r_s = -.30$, $p < .05$), (b) for private assessments ($r_s = .27$, $p < .05$), (c) with fewer months of wait time before the assessment began ($r_s = -.41$, $p < .005$), and (d) a younger age at diagnosis ($r_s = -.27$, $p < .05$). The next section addresses how these findings fit with the reviewed literature.

The questions pertaining to "during the assessment" included perceptions about the assessment itself, including the waitlist to get into an assessment, parents' perceptions of how they were treated by the professional, and if they felt their concerns were being addressed as the assessment was being conducted. Results indicated that the parents who were satisfied during the assessment were only the ones who had a shorter wait time to get assessed before the assessment began ($r_s = -.49$, $p < .001$).

Questions pertaining to "after the assessment" included the parents' perceptions about how the final diagnosis was disclosed, their understanding of the assessment report, and if any ABA agencies or behavior consultants were recommended for treatment. Additional findings from this analysis concluded that satisfaction after the assessment was higher more affluent families ($r_s = .27$, $p < .05$) and with fewer months of wait time before the assessment began ($r_s = -.45$, $p < .001$). In addition, respondents who had a private assessment (a) were older ($r_s = .27$, $p < .05$), (b) were more affluent ($r_s = .42$, $p < .005$), (c) were more likely to have a boy being assessed ($r_s = -.27$, $p < .05$), and (d) had fewer months of wait time before the assessment began ($r_s = -.58$, $p < .001$). It can be safely concluded that a long wait to get assessed is the common denominator for dissatisfaction across families who chose the government assessment route or the private assessment route. The next section shows the interpretations of these findings as they are related to private ASD assessment.

Interpretation of Findings Related to Private Assessment

This study added a new contribution to the literature, which was the private ASD assessment process. This is a significant gap in the literature as no studies so far have compared satisfaction results across the government or private routes when obtaining an ASD diagnosis. The only literature found on private assessment was reported in a study conducted by Keenan, Dillenburger, Doherty, Byrne, and Gallagher in 2010 in which these researchers stated that parents sought out private assessments rather than relying on publicly funded assessments because the average wait time for a private assessment was only about 2.5 months. These researchers further argued that there are limitations to the private assessments such as the fact they are expensive and quality control is not that consistent coming from two separate sources (government funded assessments and private assessments) rather than from just one reliable source (Keenan et al., 2010). Therefore, BC in relation to the timeliness and effectiveness of government funded diagnosis for families.

In this study, I found that parents who chose the private assessment route were older, more affluent, more likely to have a boy with ASD being assessed, and had fewer months of wait time. With regards to parental income, these results make sense. A private diagnosis in BC can be very expensive and ranges upwards depending on the complexity of the child's case (Autism Funding in BC, 2015). Therefore, families who are more affluent are the ones who would most probably access a private assessment versus waiting up to 1 year for a government-funded assessment. These families who obtain their diagnosis quickly can also access the provincial funding of $22,000 a year per child and begin their critical ABA treatment for their child at a younger age.

In summary, the major conclusion from the study was namely that the level of dissatisfaction for families was mainly due to the lengthy waitlist for an ASD diagnosis through the government funded route. There are also minor waitlists with the private assessment route of up to a few months as this study found. Additional findings also suggested that private families who pursued private assessments tended to be more affluent, which allows them to access the private assessment clinics than parents whose income level was lower. These results help fill in the gap in the literature since the length of delay of a diagnosis is such a neglected area of research in BC. Further research could shed more light onto the generalizability of these findings. In the later sections, this chapter addresses how these findings fit with the reviewed literature and theoretical base.

Literature Review and Research Findings

In this section, I discuss how the findings from this study relate to the literature review that was conducted as the foundation for this study. The first section shows the findings in relation to the hypothesis and provides explanations of those findings. The next section involves the major conclusions of the study and relate them back to the literature review.

The data analysis supported all three of the null hypotheses for the formulated research question, stating that there is no relationship between the level of parental satisfaction before assessment, during assessment, and the type of diagnostic process (private or government). It is worth mentioning a nonsignificant effect of the type of assessment (private versus government) yielded by the repeated measures ANOVA ($p = .08$). This finding indicated that private-assessment families tended to be more satisfied than the government assessment families. This finding may have been more significant if the study was not statistically underpowered and more participants were recruited to increase the sample size. This research study comparing government versus private families is new in the research, and this present study adds to the literature on ASD assessment. Therefore, due to the exploratory nature of the study, findings regarding the private assessment route that are significant at the p value < 10 level were noted to add to the literature and suggest possible avenues for future research. The significance of these results will be further discussed in the recommendations section.

A major conclusion from this study is that families who had shorter wait times were more satisfied with the assessment process than families who waited significantly longer. These results are consistent with previous research conducted in the area of ASD assessment, which have continuously shown that one of the critical variables impacting parental satisfaction in the length of delay parents experience despite already being aware of the symptoms ASD in their children (Howlin & Moore, 1997; Mandell et al., 2005; Werner et al., 2005). This late diagnosis can evoke negative feelings in parents including hostility, confusion, and uncertainty, and avoidance of the child access to appropriate early intervention services are delayed (Wiggens et al., 2006).

I also found that the longer wait times for an ASD assessment were via the government funded route with an average wait of 9 months, compared to 4 months privately, which is an issue that has not changed for families 8 years later in BC. These wait times remain the same after researchers Siklos and Kerns published their study in BC back in 2007 that also examined the parental hardships when obtaining a diagnosis of ASD in BC. The average age of the children getting diagnosed was 5 years old after a lengthy wait back in 2007 (Siklos & Kerns, 2007), and in this present study, the average age of the children getting diagnosed was 4.5 years of age, which shows that children are still being diagnosed later rather than earlier. The negative impact of receiving a late diagnosis on child progress will be discussed in a later section. This late timing of an ASD diagnosis as reflected in this present study is also consistent with results from previous research that parents have concerns about their children at an early age but an actual diagnosis of autism is not provided until they are close to or well into school age (Charwarska et al., 2007), which represents a flaw in BC regarding the early detection and diagnosis of ASD. Consistent with the previous research, Mansell and Morris (2004) found that an early and quicker diagnosis was a key contributor to reducing parental stress.

Although the hypotheses were not supported by the data, there were some additional nonsignificant findings that should be noted. Private families tended to have more satisfaction before the assessment (p = .06) and after the assessment (p = .07). A review of the private autism assessment process in BC would help interpret these findings. In BC, a family seeking a private diagnosis is responsible for the costs associated with the diagnosis and need to ensure that the clinical psychological assessment is consistent with BCAAN standards (Ministry of Children and Family Development, 2013). Private assessments are not covered by any Ministry funding, so these agencies conduct these assessments for a significant monetary gain. These highly skilled professionals are not in the "assessment hub" of government-mandated assessments that consist of a major backlog of assessments. According to the BCAAN codirector Dua, even as far back as 2008, almost 1,400 children were referred to the BCAAN network for a government funded diagnosis, which created a large backlog. The numbers for a BCAAN assessment are steadily increasing, thus families are "private queue-jumping" for an autism assessment (The Georgia Post, 2008). Therefore, private professionals can take their time with their clients and be more thorough in explaining the process before, during, and after the assessment. Regarding "prior to assessment" satisfaction, previous research by Sansosti et al. (2012) has confirmed that parents enter a practitioner's office with significant concerns and confusion about their child's current functioning and do not know what to do. Similarly, practitioners are also in this state of uncertainty regarding what the best approaches are for diagnosing a child with ASD and ultimately providing recommendations for ASD treatment in this continuously evolving field (Sansosti et al., 2012). This current study showed that parents who chose the private ASD assessment route had a more positive experience than the government funded assessment families before the assessment began, including being more informed about who their child's diagnosing professional was, understanding the ASD diagnosis process from beginning to end, and feeling that their diagnostician really understood their experience through the diagnostic process. In addition, these private-assessment families had a more positive experience than government funded families after the assessment was completed because the practitioner provided information and recommendations for effective intervention services needed for their child. This result is consistent with Gasper de Alba and Bodfish's (2011) research that found that parents were more interested in learning about the possible interventions at the time of diagnosis rather than dwelling on the getting more information about the disorder itself. With regards to less satisfaction after the assessment for government funded families, this result was consistent with research conducted by Osborne and Reed (2008) who found that after parents have adjusted to receiving the diagnosis, they reflected back and stated that they would have been more satisfied if they had been given more information about the types of intervention available for their children. These researchers further concluded that this reflection provided by parents regarding the benefit of receiving post diagnosis support might help with the process of adjustment and adaptation after receiving a devastating diagnosis of ASD (Osborne & Reed, 2008).

Although the current study did not find an overall positive correlation of satisfaction scores between the two groups (government and private), the aforementioned findings to contribute to the current literature. This research found that a lengthy wait time is a contributing factor with parental dissatisfaction no matter what route the family chooses. Consistent with previous studies, at the time of diagnosis, most parents wish for a quicker and easier process (Goin-Kochel et al., 2006; Mansell and Morris, 2004).

Families who are more affluent are more able to access private assessments which are costly to the average family. This financial aspect of the private assessment route imposes implications for equality of access between the affluent and lower income families. Those children whose families are financially capable of accessing the private ASD assessment will receive the critical treatment earlier than the children who are waiting significantly longer for an ASD diagnosis. These findings add to the current literature while opening further research opportunities comparing the two routes of diagnosis. These results can lend new insight into policies and procedures for practitioners. Implications for these findings will be further discussed in the recommendations section.

Theoretical Framework and Research Findings

The theoretical framework for this study, Hochbaum's Health Belief Model, supported parental perceptions of their ASD diagnostic experience in relation to their four proposed concepts: a) perceived threat (which includes perceived susceptibility and perceived severity as its subcomponents), b) perceived benefits, c) perceived barriers, and d) self-efficacy. When a family seeks a diagnosis of autism, they are confronted with many difficult decisions including where they should go to get diagnosed, who the diagnostician is, what treatments are available etc. (as discussed in chapter 1). These variations in a family’s health-related decision are based upon their perceptions of: acceptance of the diagnosis; impact of the disorder; benefits and barriers of treatment; and their self-efficacy (Wildman, 2006). Although this study did not find an overall relationship between satisfaction scores before, during, and after and ASD assessment between the private and government assessment route, other additional findings can help interpret a relationship to its theoretical base.

The HBM model can be applied to parents with children with autism because according to this model, parents of children with autism have different perceptions and beliefs about their child’s disorder and available treatments. Firstly, when applying the HBM model, the *perceived threat* refers to the degree of impact this ASD diagnosis entails for their child’s development. In this study, satisfaction scores across both the government and private route indicated that satisfaction was higher when the child was younger, for families who chose a private assessment, and those families who had a shorter wait time before the assessment. A lengthy wait time for families can be referred to as the perceived threat of the HBM model and how this late diagnosis impacts the overall course of their child's prognosis. Previous research has shown that parents reported that they had identified their child’s possible autistic features and tendencies as early as 18 months and sought medical help when they were 24 months. Even though these parents recognized the symptoms very early in their child’s life, they expressed frustration with how long it took to actually obtain the diagnosis, namely between 3.5 to 6 years of age (Werner et al., 2005). This late timing of receiving a diagnosis leads to feelings of hostility, confusion, and uncertainty, and avoidance of the child because it in turn leads to slower access to appropriate early intervention services (Wiggins et al., 2006).

Second, parents express varying beliefs about the course and outcome of ASD treatment of ASD, which is referred to the HBM model at the perceived benefit. In addition these families need to weigh all the negative consequences attached to treatment models including the cost, side effects/dangers, and convenience level involved which is referred to the perceived barrier. This study found that parents who were more affluent, received a private assessment, and had a shorter wait time experienced a perceived benefit because they more satisfied "after the assessment" with (a) how sensitively the final diagnosis was disclosed (b) they had a better understanding of the assessment report and (c) they had ABA agencies or behavior consultants recommended to them for treatment. Consistent with perceived benefit, in this study, private-assessment families who were more affluent are able to better understand the condition and nature of autism, and therefore are more proactive in getting the diagnosis and treatment faster than parents who wait on the government funded assessment waitlist. In addition, they are better equipped to face perceived barriers because they were probably given the support by their diagnosing professional to weigh all the negative consequences attached to treatment models including the cost, side effects/dangers, and convenience level involved. This is consistent with previous research which found that with the even though there are tight constraints of available time and resources available, it is still critical that ASD diagnosticians involved in the assessment of ASD recognize the growing concerns parents have at the time of diagnosis so they can be better equipped to effectively provide the most up to date information about the course of ASD and its treatment (Gasper de Alba & Bodfish, 2011).

Finally, if these professionals have taken the time at the support and guide parents through the process, they will use their beliefs and self-perceptions to follow through with the procedures necessary to achieve the best outcomes they desire for children (self-efficacy; Wildman, 2006). Satisfaction after the assessment, such as in this present study where private families had more satisfaction post assessment, is enhanced if professionals actively involve parents in the sessions and allow them to build a trusting relationship as they will need support from the team for many years even after the diagnosis (Mockett et al., 2011).

In conclusion, the HBM is applicable in many ways to families who are experiencing a diagnosis of ASD. According to this model, parents of children with autism have different perceptions and beliefs about their child's the course and condition which can affect their levels of perceived threat, perceived benefits and perceived barriers. In addition, the families ASD experience can affect a parent's level of perceived barriers and self-efficacy of the disorder because of the potential concerns regarding what scientifically validated intervention is appropriate for their child. The next section will discuss the limitations of this study.

Limitations of the Study

This section will discuss several limitations that were encountered with this study. Some of these limitations include an underpowered study, participant recollection of the assessment phase, social desirability bias, small sample size, and generalizability of the results.

First, a sample of 74 participants was chosen to detect a medium effect size. After a 2-month recruitment phase, only 63 participants returned their questionnaires back to the researcher. Therefore, this study may have been underpowered, and this sample size might not have been large enough to detect a small effect size as desired.

Another limitation may be that participants may have skewed the data by giving an inaccurate responses pertaining to parental perceptions of the ASD diagnosis. For example, this study consisted of families who had to recount their memory of the diagnosis feedback session either recently or up to 3 years past the diagnosis. Therefore, the inaccuracy of the perception of the ASD diagnosis based on how much detail they remembered from that day may not be accurate for families who received a diagnosis 3 years ago versus families who received a recent diagnosis in the last few months to 1year.

Third, it is imperative to note that the demographic and parent perceptions questionnaires are self-report inventories. Therefor there was some social desirability bias detected to be present in the answers. For example, some families reported that after the BCAAN assessment they were satisfied that a video of ASD was shown them post assessment. However, in this region of BC, the BCAAN network does not show videos of ASD after disclosure, as this not a standard practice in assessment. Therefore, these types of inaccurate responses may have skewed the data.

Fourth, the sample size of this study was quite small and it was restricted to families who had children under the age of 6 in BC. However, there is a large population of families whose children are being diagnosed over the age of 6, but they were not included in this study. This study may have been more representative of the ASD population in BC if the sample size was increased and if it included participants with children over the age of 6. Children over the age of 6 were excluded from this study to better control any excess variables and the children under the age of 6 are prioritized for an ASD assessment in BC thus allowing access to more participants in BC. In addition, the sample was drawn from individuals only living in BC, Canada and does not fully represent all populations across Canada or North America as a whole, thus limiting generalizability of the test results.

Finally, only those participants were invited to participate if they were willing to complete an online survey representing a self-selection bias issue. The survey was only accessible via the Internet and the participants would need to be computer literate to participate. The methodological flaw resulting from this is that the sample of participants may be assumed to be from a higher socioeconomic status and higher educated than the general population (Bodfish & De Alba, 2011). The next section will discuss conclusions and implications for this study.

Conclusions and Implications

The major conclusion from this study is that parents across BC, whether they choose the government funded or private assessment route, are dissatisfied with the lengthy wait time for an ASD assessment in BC. No improvements have been made to accommodate the wait list which can still be an upwards to 18 months after this published information by Siklos and Kerns in 2007. As discussed previously, this late timing of receiving a diagnosis leads to feelings of hostility, confusion, and uncertainty, and avoidance of the child because it in turn leads to slower access to critical early intervention services the child needs to progress (Wiggins et al., 2006). These lengthy delays have several humanitarian implications for families.

Many decades of research have effectively shown that early intervention services, before the age of 3, drastically reduce the severity of autism symptoms in children with ASD, (McEachin et al., 1993; Sansosti et al., 2012; Smith et al., 2000) while increasing academic achievement (National Research Council, 2001). Therefore, if the research clearly shows that best outcomes can be achieved when intervention starts early, then these delays are interfering with the child's lifelong progress. The next section will discuss more details about the humanitarian aspects and social justice implications for a delayed autism assessment.

Inequality Concerns

Early intervention for autism is the pathway to achieving best outcomes in the future. Early intervention is only accessible in BC once a diagnosis is made, at which time parents have access to provincial funding for treatment services in the amount of $22,000 a year for children under 6 and $6000 a year for children over 6. Early diagnosis and intervention can lead to more positive outcomes for children including cognitive performance, language skills, and adaptive behavior in certain groups of children with autism by drastically reducing their autism symptomology (McEachin et al., 1993; Sansosti et al., 2012; Smith et al., 2000; Warren et al., 2011). Therefore, delays of up to 1 year cost $22,000 for the family or a year of funding per child in BC to buy those intervention services, which in turn leads to the loss of the critical ABA intervention that these children need to reach better outcomes. In addition, waiting on a lengthy government funded waitlist for a diagnosis imposes an inequality issue in that these children do not have an equal opportunity to thrive and reach equal outcomes as their normal peers are achieving. There is a clear disparity between the affluent and the low-income families, as families who have the financial means can access a private diagnosis whereas the other families remain waiting on the lengthy government funded waitlist. There are lifelong implications and loss of a quality of life for these individuals if they do not receive their early intensive intervention on time including education, career, relationships, marriage etc. A study conducted in Sweden by Billstedt, Gillberg, and Gillberg (2005) found some interesting results regarding adult outcomes. They found that children who had early intervention with positive gains in their cognitive IQ level and communicative phrase speech by 6 years of age achieved positive outcomes as adults in the areas of employment, education, independent living, and social relationships. However it is important to note that individuals with Asperger's had a better outcome that adults with autism who tended to have more restricted and isolated lives with no social relationships (Billstedt et al., 2005). This study will contribute to social change for these families and children because it will publish updated data on the lengthy ASD waitlist in BC and consequences for a child's future progress if they do not receive early intervention in a timely manner. Also, this study highlighted the inequalities associated with accessing a private diagnosis. It is apparent from the findings that private-assessment families are slightly more satisfied with the ASD diagnosis because they had the financial stability to access the assessment over low-income families. Therefore, inequality exists in BC as private-assessment families get the diagnosis faster and in turn have faster access to the government funding for intervention services. In addition, recommendations will be made and created by the researcher for dissemination to the BCAAN network and private diagnostic clinics to alleviate the wait time and provide the necessary resources parents need when going through this complex ASD diagnosis process. The next section will discuss the recommendations for action and social change that would help the families and children of BC who are waiting for a diagnosis of ASD.

Recommendations for Action

The fact remains that parents are more frustrated and dissatisfied with the ASD diagnostic process in BC because few improvements have been made to accommodate the wait list which can be an upwards to 18 months. Additional findings from this study indicated that a long wait list, low-income level, and the age of a child could significantly impact a parent's satisfaction of the assessment process. Significant changes need to be made within the infrastructure of the BC Health Care system to help families with children with autism have more options for assessment so their children can receive the critical treatment they need to make lifelong progress. The next sections will discuss some recommendations for future research, practice, and policy and implications for social change.

Implications for Social Change

The implications for social change include pertinent changes at the societal policy and practitioner level in order to address the major concerns with the ASD diagnostic experience including the long wait list, the lack of information and resources provided after a diagnosis, and the financial burden of seeking a private diagnosis. This study is an attempt to improve reform efforts in the health care system in BC because there is a definite inequality for families when trying to access an ASD diagnosis in BC. The disparity between the affluent and the lower income families poses implications for diagnosis and treatment for children with ASD. Lower income families who have to wait on a lengthy government waitlist lose a significant amount of monthly funding to access the critical early intervention their children.

Practitioner Level Recommendations

This subsection will discuss some practitioner level recommendations that can be incorporated into the current practice of psychologists who conduct ASD assessments in BC in the government funded or private route in BC. Although this study did not find a direct relationship between overall satisfaction scores and the type of diagnostic process, some additional findings did shed some light on changes that need to be made at the practitioner level to provide a more positive experience for families receiving a diagnosis of ASD for their child. In this study satisfaction was higher before the assessment and after in their feedback sessions for parents indicating that the private model may be providing more time and resources for their families.

Before the assessment, it would be helpful for all practitioners to provide written materials and information regarding what the diagnostic process entails, who the practitioners are, and how long the appointments are etc. Consistent with previous studies, parents are generally more satisfied when they are provided with information at the onset of the referral, even if the referral was based only on a suspicion of ASD (Brogan & Knussen, 2003; Sloper & Turner, 1991). This written information would be greatly beneficial to families of children with autism being diagnosed in BC which include: written information of the ASD about what it is and its symptoms, the purpose of the assessment, appointment dates and times, name and credentials of all the clinicians involved, the structure of the assessment and an accurate timeline for completion, and answers to most frequently asked questions polled from previous feedback sessions. In addition another recommendation for practitioners is to prepare families to answer developmental history questions that can be hard to retrieve from memory (Mockett et al., 2011). Parents have stated that getting this information prior to starting the assessment process would help them prepare and formulate pertinent questions they feel they should ask when their child is given a devastating diagnosis rather than feeling confused and frustrated (Braiden et al., 2010).

Families in the present study who expressed some dissatisfaction during and after the assessment is consistent with other research conducted in the area of ASD assessment. Researchers have found that many parents are not satisfied with the diagnostician's explanation of the core symptoms of autism and leave the initial assessment with significant concerns (Mockett et al., 2011). Most importantly, consistent with other studies on satisfaction, parents are mostly dissatisfied after the assessment with understanding the diagnosis and how to seek intervention (Bodfish and De Alba, 2011; Braiden et al., 2010; Howlin & Moore, 1997; Mockett et al., 2011; & Siklos & Kerns, 2007). Families need more guidance on the various interventions for ASD including behavioral intervention, speech and language therapy, occupational therapy, medical treatments, and educational placements. The present study found that private-assessment families had more satisfaction after the assessment possibly due to the fact that the professional provided more information about treatment options. In BC, the ABA services are quite vast with behavior consultants on the RASP list having varying degrees of experience and training. At this time there is no regulatory professional body overseeing the treatment delivered by the behavior consultants in BC; therefore parents have a daunting task of narrowing down what service provider(s) are more credible than others. Therefore, it is the obligation of diagnosticians to research the credibility of ABA consultants and guide parents in the right direction. Recommendations for the final feedback session following diagnosis have been documented by several researchers and include Braiden et al., (2010) Mockett et al., (2011), Sansosti et al., (2011) include the team booking a longer feedback session where parents can openly ask their questions have their concerns addressed and practitioners can offer information about treatment services in BC. In addition, practitioners should provide written summary letter of the diagnosis before the report is issued which clearly states the outcome of the assessment, who the professionals were on the diagnostic team, and the date of diagnosis. Also, parents should walk away with written information regarding local supportive parent support groups, autism resource centers, paraprofessional services, and a list of accredited behavior consultants and agencies in BC.

Another final recommendation as stated by Sansosti et al. (2011) in their study, is that it is critical that practitioners in BC educate themselves on the most empirically validated intervention programs and make the appropriate referrals based on accurate progress monitoring of those programs by working professionals in the field of ABA. Findings from Sansosti's (2011) study found that although parents had an adequate understanding of scientifically validated treatments for autism for their children, this knowledge came from self-education and through the Internet. More concerning is the fact that these families believed that non-empirically supported interventions like the gluten-casein free diet or sensory integration therapy were equally effective as the empirically supported interventions which may lead to negative outcomes in the future. Therefore, it is the obligation of diagnosing and treating professionals to guide parents into choosing scientifically validated treatment approaches to autism while discussing the ethical implications of non-empirical treatments.

A final recommendation for families in BC after a difficult diagnosis is for diagnosing professionals to make a referral for counselling services to monitor the mental health of parents who are hit with a diagnosis of ASD. Siklos and Kerns (2007) that BC parents react negatively to a diagnosis of ASD for their child because of their high stress levels and it is important for professionals to help parents deal with these initial reactions. This will help alleviate pressure as the families begin to navigate the post diagnostic support in a continued saturated service delivery system that has not changed since Siklos and Kerns's (2007) study. The next section will discuss policy level recommendations that are needed in BC to help improve the ASD diagnostic process.

Policy Level Recommendations

This section will discuss some pertinent recommendations for policy makers in the field of autism in BC. At the policy level, this present study had similar findings to other studies conducted in the field regarding the ASD diagnostic process that a lengthy wait time is one of the core reasons of dissatisfaction for families who have children with autism (Howlin & Moore, 1997; Mandell et al., 2005; Werner et al., 2005). First, there should be adjustments in policies in order to effectively cater to the needs of families seeking a diagnosis of ASD in BC. With the waitlist being so long with the government funded route, the BC Health Care system should be providing more trained professionals conducting ASD assessments in conjunction with improvements with licensure requirements and ASD training. More options for private ASD assessment is also warranted so families have that option if the waitlist is too long through the government assessment process.

In addition, there should be more government funding to develop more BCAAN contracted sites for publicly funded diagnosis for ASD as currently there are only a handful in all of British Columbia. At the larger level, the infrastructure of the BC and Canada as a whole needs to endorse the notion similar to the Individuals with Disability Act (IDEA) of 1975 that is implemented in the United States to create prevention programs to children who are on a waitlist. IDEA was originally enacted by Congress in 1975 to allow all children with disabilities the right to a free education and treatment like all typically developing children (Autism Community, 2015). In particular, IDEA Part C with new legislation in 2011, recognizes the "urgent and substantial need" to help infants and toddlers with disabilities including autism to get the necessary early intervention before a diagnosis is even made by applying for grants to the federal government for services for children birth to 2 years (U.S. Department of Education, 2015, para. 3). This new legislation was developed for the sole reason to improve the services and outcomes for infants and toddlers and their families with disabilities in the United States. These types of programs while on a waitlist for children would help alleviate some autism symptoms and start the journey towards progress much faster than an unnecessary delay that could cause lifelong implications.

One such preventative measure for children on the BC autism assessment waitlist could be pilot projects consisting of the new empirically validated treatment for toddlers called the Early Start Denver Model (ESDM). The ESDM model is considered a structured, data driven, and relationship-based intervention with direct parent involvement encouraging an early start to their child's intervention with a focus in increasing their social-emotional, cognitive, and language development. The goal of ESDM is to increase the rates of development in the critical areas stated above and to decrease the symptomology of autism (University of California Davis Mind Institute, 2015).

In conclusion, this study may not have found a relationship between overall satisfaction (before, during, and after) and the type of diagnostic process (government versus private), but some important insights were gained such as what factors can influence the parental satisfaction of the ASD diagnostic process, namely, that a lengthy wait time leads to dissatisfaction. This factor of wait time is crucial to families and can immediate and lifelong implications on a child's progress; therefore, the appropriate practitioner and policy recommendations need to be implemented to help the BC Health Care system make the changes for a quicker turn around for ASD assessments, which in turn allows families to seek intervention services for their child's progress.

Recommendations for Future Research

The research findings from this study demonstrated that a parent's satisfaction level is influenced by how long they need to wait for the child to be assessed for a diagnosis of ASD. However, future research is needed to examine other aspects of the diagnostic process that could not be addressed in this study. This section will discuss some areas of future research that will enhance the area of parental perspectives of the ASD diagnostic process and add to the current literature including some methodological enhancements and expanding the research.

Methodological Advancements

This study did not find a positive relationship between satisfaction scores and type of assessment (government versus private) and any significant correlations before, during, or after the assessment, thereby prompting for methodological advances needed to broaden the study and clarify this relationship. Firstly, this study only had 63 participants who children were under the age of 6. Future studies should be conducted where the sample size and population is increased for more generalizability of the results. For example, future studies should include the older children who are diagnosed over the age of 6 to see if satisfaction of the ASD diagnostic process is different in BC for parents who have older children. The current study was more of an exploratory study that used a convenience sample of the population.

Secondly, this study was purely quantitative in nature and required participants to complete an online survey. Future studies should add a qualitative component as it provides a "voice" for the parents concerns which may in turn reveal more pertinent information which can be neglected by quantitative studies. It would be vital to combine the use of a self-administered questionnaire with an in-depth interview of the family's journey when they received a diagnosis of autism so the researcher can gain a more thorough understanding of what parts of the assessment process were positive and negative.

Expanding the Research

First, the major finding from this study is that regardless of seeking a diagnosis through the government funded or private ASD assessment route, the most critical factor leading to dissatisfaction is the lengthy wait time to receive a diagnosis. At this time, no overall difference in satisfaction between the government funded or private assessment was found, but it is evident that the private assessment route is a shorter wait for families. There is no research conducted on the area of parental perspectives of the private assessment route. Future research should further investigate aspects of the private assessment that lead to more positive outcomes for families since Keenan et al., (2010) have shown that families will turn to a private assessment if the waitlist is too long.

Second, additional findings in this study prior to the Bonferroni adjustments were consistent with other studies on satisfaction, in that parents are mostly dissatisfied after the assessment with understanding the diagnosis and how to seek intervention (Bodfish and De Alba, 2011; Braiden et al., 2010; Howlin & Moore, 1997; Mockett et al., 2011; Siklos & Kerns, 2007). Therefore, future studies should add another component to the study, which is to investigate the satisfaction of the treatment program chosen by the parent after guidance by the diagnosing professional. This will shed some more light on the professional's knowledge base of the scientifically validated interventions in BC and help identify the gaps in the professional's training. As discussed by Sansosti et al. (2011), this type of research could help in the development of appropriate in-service training and workshops to enhance the diagnostician's knowledge and awareness of the ABA treatment programs available to parents in BC so they can more effectively guide those families in the right direction.

Conclusion

This study was conducted with a sample of parents who have children diagnosed with autism under the age of 6 who went through a government funded or private ASD assessment for their child. The research was designed to collect data from a self-administered questionnaire to examine if there was a relationship between satisfaction scores and the type of assessment parents chose, namely, government funded or the private assessment route. The results of the study indicated no overall difference in mean satisfaction scores between government and private assessment (Hypothesis 1), no overall change in satisfaction scores during the course of the assessment process (before, during, and after assessment (Hypothesis 2) and no significant interaction effect for the type of diagnostic process with the "satisfaction timing" namely, before, during, and after (Hypothesis 3). However, additional findings found some significant correlations with the underlying factor of dissatisfaction in the diagnostic process being a lengthy wait time. Other findings prior to some statistical adjustments revealed that parents who chose the private assessment route were typically more satisfied before and after the assessment, were more affluent, and had waited less time than families who chose the government funded route.

Findings from this study are consistent with previous studies in the literature suggesting that parents express more frustration during the diagnosis process and disclosure if they have experienced longer delays in receiving a diagnosis (Howlin & Moore, 1997; Mandell et al., 2005; Werner et al., 2005). Clearly, this study has shown that delays in diagnostic process in BC have remained stagnant since the last study conducted by Siklos and Kerns in 2007. Changes in the ASD diagnostic process is vital at this time in BC as these lengthy delays have lifelong implications for children and may affect their long-term progress if the window of opportunity for the critical ABA treatment is missed. Findings from this study provide important insights into parental satisfaction and the type of ASD diagnostic process, thus opening the door for future studies to broaden this knowledge and make the appropriate changes. These findings are critical to the BC healthcare system and the presenting practitioner and policy recommendations should be implemented to pave the way for social justice for our children with autism.

References

American Academy of Pediatrics. (2010). Racial and ethnic disparities in the health and health care of children. *Pediatrics, 125*, e979-e1020. http://dx.doi.org/10.1542/peds.2010-0188.

American Psychiatric Association. (2013). Autism Spectrum Disorder. DSM-5 Autism Spectrum Disorder fact sheet. Retrieved from http://www.dsm5.org/Documents/Autism%20Spectrum%20Disorder%20Fact%20Sheet.pdf

ACT-Autism Community Training. (2013). Retrieved from http://www.actcommunity.ca/

Autism Community. (2015). *IDEA*. Retrieved from http://www.autism-community.com/education/idea/

Autism Funding in BC or Autism Funding for Dummies. (2015). Autism diagnosis. Retrieved from http://asdfunding.com/

Autism Speaks Canada. (2013). Accessing treatment. Government funded programs and services. Retrieved from http://www.autismspeaks.ca/about-autism/accessing-services/

Bailey, D.B., Golden, R.N., Roberts, J., & Ford, A. (2007). Maternal depression and developmental disability: Research critique. *Mental Retardation and Developmental Disabilities Research Reviews; Special Issue: Families of Children with Developmental Disabilities, 13*, 321-329. http://dx.doi.org/10.1002/mrdd.20172

Billstedt, E., Gillberg, I. C., & Gillberg, C. (2005). Autism after adolescence: population-based 13 to 22-year old follow-up study of 120 individuals with autism diagnosed in childhood. *Journal of Autism and Developmental Disorders, 35*, 351-360. http://dx.doi.org/10.1007/s10803-005-3302-5

Blacher, J., & McIntyre, L.L. (2006). Syndrome specificity and behavioral disorders in young adults with intellectual disability: Cultural differences in family impact. *Journal of Intellectual and Developmental Disabilities, 50*, 184–98. http://dx.doi.org/10.1111/j.1365-2788.2006.00768.x

Bowlby, J. (1980*). Attachment and loss*. New York, NY: Basic Books.

Braiden, H.J., Bothwell, J.D., & Duffy, J. (2010). Parents' experience of the diagnostic process for autistic spectrum disorders. *Child Care in Practice, 16*, 377-389. http://dx.doi.org/10.4135/9781446213872

Brogan, C. A., & Knussen, C. (2003). The disclosure of a diagnosis of an autistic spectrum disorder: Determinants of satisfaction in a sample of Scottish parents. *Autism, 7*, 31-46. http://dx.doi.org/10.1177/1362361303007001004

Bryson, .S., Rogers, S., & Fombonne, E. (2003). Autism spectrum disorders: Early detection and intervention, education and psychopharmacological treatment. *Canadian Journal of Psychiatry, 48*, 506–516. http://dx.doi.org/10.4324/9781410611260

Centers for Disease Control and Prevention (CDC). (2007). *Prevalence of —autism spectrum disorders --- Autism and developmental disabilities monitoring network, Six Sites*.). Atlanta, GA: Author,

Centers for Disease Control and Prevention (2012). CDC estimates 1 in 88 children in United States has been identified as having an autism spectrum disorder.

Retrieved from http://www.cdc.gov/media/releases/2012/p0329_autism_disorder.html

Chance, P. (2003) *Learning and behavior* (5th ed.). Toronto, Canada: Thomson-Wadsworth.

Chawarska, K., Klin, A., Paul, R., & Volkmar, F. (2007) Autism spectrum disorder in the second year of life: Stability and change in syndrome expression. *Journal of Child Psychology and Psychiatry, 48*, 128–138.

Creswell, J. W. (2009). *Research design: Qualitative, quantitative and mixed methods approaches* (3rd end). Thousand Oaks, CA: Sage.

Cuccaro, M., Wright, H., Rownd, C., Abramson, R., Waller, J., & Fender, D. (1996). Professional perceptions of children with developmental difficulties: The influence of race and socioeconomic status. *Journal of Autism and Developmental Disorders, 26*, 461–469. http://dx.doi.org/10.1007/bf02172830

Dawson, G., Rogers, S., Munson, J., Smith, M., Winter, J. Greenson, J… Varley, J. (2010). Randomized, controlled trial of an intervention for toddlers with autism: *Early Start Denver Model, Pediatrics, 125*(1), e17-e23. http://dx.doi.org/10.1542/peds.2009-0958

Dua, V. (2008, May 7). Families wait in limbo for autism assessments. *The Georgia Post***.** Retrieved from http://www.straight.com/article-144666/families-wait-limbo-autism-assessments

Dumont-Mathieu, T., & Fein, D. (2005). Screening for autism in young children: The modified checklist for autism in toddlers (M-CHAT) and other measures. *Mental*

Retardation and Developmental Disabilities Research Reviews, 11, 253–262. http://dx.doi.org/10.1002/mrdd.20072

Eaves, R.C., & Milner, B. (1993). The criterion related validity of the childhood autism rating scale and the autism behavior checklist. *Journal of Abnormal Child Psychology, 21*(5), 481-492. http://dx.doi.org/10.1007/bf00916315

Faul, F., Erdfelder, E., Buchner, A., & Lang, A. G. (2009). Statistical power analyses using G*Power 3.1: Tests for correlation and regression analyses. *Behavior Research Methods, 41*, 1149-1160. http://dx.doi.org/10.3758/brm.41.4.1149

Foxx, R.M. (2008). Applied behavior analysis treatment of autism: The state of the art. *Child and Adolescent Psychiatric Clinics of North America*, *17*, 821-834. http://dx.doi.org/10.3758/brm.41.4.1149

Gasper De Alba, M. J., & Bodfish, J.W. (2011). Addressing parental concerns at the initial diagnosis of an autism spectrum disorder. *Research in Autism Spectrum Disorders, 5*, 533-539. http://dx.doi.org/10.1016/j.rasd.2010.07.009

Goin-Kochel, R. P., Mackintosh, V. H., & Myers, B. J. (2006). How many doctors does it take to make an autism spectrum diagnosis? *Autism, 10*, 439–451. http://dx.doi.org/10.1177/1362361306066601

Graungaard, A.H., & Skov, L. (2006). Why do we need a diagnosis? A qualitative study of parents’ experiences, coping and needs, when the newborn child is severely disabled. *Authors, Child: Care, Health and Development 33*, 296–307. http://dx.doi.org/10.1111/j.1365-2214.2006.00666.x

Gravetter, F. J., & Wallnau, L. B. (2009). *Statistics for the behavioral sciences* (8th ed.). Belmont, CA: Wadsworth Cengage Learning.

Gray, L. A., Msall, E. R., & Msall, M. E. (2008). Communicating about autism: Decreasing fears and stresses through parent-professional partnerships. *Infants & Young Children, 21*, 256–271. http://dx.doi.org/10.1097/01.iyc.0000336539.52627.e4

Guralnick, M. J. (2005). Early intervention for children with intellectual disabilities: Current knowledge and future prospects. *Journal of Applied Research on Intellectual Disabilities, 18*, 313-324. http://dx.doi.org/10.1111/j.1468-3148.2005.00270.x

Hasnat, M. J., & Graves, P. (2000). Disclosure of developmental disability: A study of parent satisfaction and the determinants of satisfaction. *Journal of Paediatric Child Health, 36*, 32-35. http://dx.doi.org/10.1046/j.1440-1754.2000.00463.x

Hertz-Picciotto, I., & Delwiche, L. (2009). The rise in autism and the role of age at diagnosis. *Epidemiology, 20*(1), 84-90. http://dx.doi.org/10.1097/ede.0b013e3181902d15

Hillman, J. (2006). Supporting and treating families with children on the autistic spectrum: The unique role of the generalist psychologist. *Psychotherapy: Theory, Research, Practice, Training, 34*, 349-358. http://dx.doi.org/10.1037/0033-3204.43.3.349

Howell, J., Miller, P., Park, P.H., Sattler, D., Schack, T., Spery, E…, Palmquist, M. (2012). *Reliability and Validity*. Writing@CSU. Colorado State University.

Retrieved from http://writing.colostate.edu/guides/guide.cfm?guideid=66.

Howlin, P., & Asgharian, A. (1999). The diagnosis of autism and Asperger syndrome: Findings from a survey of 770 families. *Developmental Medicine and Child Neurology, 41*, 834–839. http://dx.doi.org/10.1111/j.1469-8749.1999.tb00550.x

Howlin, P., & Moore, A. (1997). Diagnosis in autism: A survey of over 1200 patients in the UK. *Autism: International Journal of Research and Practice, 1*, 135-162. http://dx.doi.org/10.1177/1362361397012003

Huang, Y.P., & Kellet, U.M., & Winsome, J.S. (2010). Cerebral palsy: experiences of mothers after learning their child's diagnosis. *Journal of Advanced Nursing, 66*(6), 1213-1221. http://dx.doi.org/10.1111/j.1365-2648.2010.05270.x.

Janz, N. K., & Becker, M. H. (1984).The health belief model: A decade later. *Health Education Quarterly, 11*, 1-47. http://dx.doi.org/10.1177/109019818401100101

Kabot, S. Masi, W., & Segal, M. (2003). Advances in the diagnosis and treatment of autism spectrum disorders. *Professional Psychology: Research and Practice, 34*(1), 26-33. http://dx.doi.org/10.1177/109019818401100101

Keenan, M., Dillenburger, K., Doherty, A., Byrne, T., & Gallagher, S. (2010). The experiences of parents during diagnosis and forward planning for children with autism spectrum disorder. *Journal of Applied Research in Intellectual Disabilities, 23*, 390-397. http://dx.doi.org/10.1111/j.1468-3148.2010.00555.x

Kugler, B. (1998). The differentiation between autism and asperger syndrome. *Autism, 2*(1), 11-32. http://dx.doi.org/10.1177/1362361398021003

Laerd Statistics. (2013). *Cronbach's Alpha (α) using SPSS*. Retrieved from https://statistics.laerd.com/spss-tutorials/cronbachs-alpha-using-spss-statistics.php

Mandell, D., Ittenback, R. F., Levy, S. E., & Pinto-Martin, J. (2007). Disparities in diagnoses received prior to a diagnosis of autism spectrum disorder. *Journal of Autism and Developmental Disorders, 37*, 1795–1802. http://dx.doi.org/10.1097/dbp.0b013e318165c7a0

Mansell, W., & Morris , K. (2004) A survey of parents' reactions to the diagnosis of an autistic spectrum disorder by a local service: Access to information and use of services. *Autism, 8*, 387–407. http://dx.doi.org/10.1177/1362361304045213

Marvin, R.S., & Pianta, R.C. (1996). Mother's reactions to their child's diagnosis: relations with security and attachment. *Journal of Clinical Psychology, 25*, 436-445. http://dx.doi.org/10.1207/s15374424jccp2504_8

McEachin, J. J., Smith, T., & Lovaas, O. I. (1993). Long-term outcome for children with autism who received early intensive behavioral treatment. *American Journal of Mental Retardation, 97*, 359-372. http://dx.doi.org/10.1177/0145445506291396

Miller, L. J., & Hanft, B. E. (1998). Building positive alliances: Partnerships with families as the cornerstone of developmental assessment. *Infant Young Children, 11*(1), 49-60. http://dx.doi.org/10.1097/00001163-199807000-00008

Ministry of Children and Family Development. (2013). *A parent's handbook: Your guide to autism programs*. Retrieved from www.mcf.gov.bc.ca/spec_needs/index.htm

Mockett, M., Khan, J., & Theodosiou, L. (2011). Parent perceptions of a Manchester

Service for autistic spectrum disorders. *International Journal of Family Medicine, 201*, http://dx.doi.org/10.1155/2011/601979

National Autism Center (2009). *The national standards project-addressing the need for evidence-based practice guidelines for autism spectrum disorders*. Retrieved from http://www.nationalautismcenter.org/pdf/NAC%20Standards%20Report.pdf

National Cancer Institute (2003). *Theory at a glance: A guide for health promotion and practice*. Washington DC: US Department of Health and Human Services.

National Dissemination Center for Children with Disabilities (2013). The little ones: Early intervention/early childhood. Retrieved from http://nichcy.org/newsletters/sept2013#ei

National Professional Development Center on ASD (2014). *Evidence-based practices*. Retrieved from www.autismpdc.fpg.unc.edu/content/about-center-2

National Research Council. (2001). *Educating children with autism*. Washington, DC: National Academy Press.

Noterdaeme, M., Amorosa, H., Mildenberger, K., Sitter, S., & Minow, F. (2001). Evaluation of attention problems in children with autism and children with a specific language disorder. *European Child & Adolescent Psychiatry,10*(1), 58–66. http://dx.doi.org/10.1007/s007870170048

Nursey, A.D., Rodhe, J.R., & Farmer, R.D.T. (1991). Ways of telling new parents about their child and his or her mental handicap: a comparison of doctor's and parents' views. *Journal of Mental Deficiency Research, 35*, 48-50. http://dx.doi.org/10.1007/s007870170048

Ohta, M., Nagai, Y., Hara, H., & Sasaki, M. (1987). Parental perception of behavioral symptoms in Japanese autistic children. *Journal of Autism & Developmental Disorders, 17*, 549–563. http://dx.doi.org/10.1007/s007870170048

Osborne, L.A. & Reed, P. (2008). Parent perceptions of communication with professionals during the diagnosis of autism. *Autism*, *12*, 309-324. http://dx.doi.org/10.1177/1362361307089517

Ozonoff, S., & Rogers, S. J. (2003). From Kanner to the millennium: Scientific advances that have shaped clinical practice. In S. Ozonoff, S. J. Rogers, & R. L. Hendren (Eds.), *Autism spectrum disorders*: A research review for practitioners (pp.3-33). Washington, DC: American Psychiatric Association.

Pearson, D., Simms, K., Ainsworth, C., & Hill, S. (1999). Disclosing special needs to parents. Have we got it right yet? *Child: Care, Health, and Development, 25*(1), 3-13. http://dx.doi.org/10.1046/j.1365-2214.1999.00086.x

Perry, A., Condillac, R. M., & Freeman, N.L. (2002). Best practice and strategies for assessment and diagnosis of autism. *Journal of Development Disability*, 61-75.

Poehlman, J., Clements, M., Abbeduto, L. & Farsad, V. (2005). Family experiences associated with a child's diagnosis of Fragile X or Down syndrome: Evidence for disruption and resilience. *Mental Retardation, 43,* 255-267. http://dx.doi.org/10.1093/med/9780195371826.003.0082

Provincial Health Services Authority. (2012). *BC Autism Assessment Network (BCAAN).* Retrieved from http://www.phsa.ca/HealthProfessionals/Autism/default.htm

Quine, L., & Pahl, J. (1987). First diagnosis of severe handicap: A study of parental reactions. *Developmental Medicine and Child Neurology*, *29*, 232-242. http://dx.doi.org/10.1111/j.1469-8749.1987.tb02141.x

Quine, L., & Rutter, D.R. (1994). First diagnosis of severe mental and physical disability: A study of doctor-parent communication. *Journal of Child Psychology & Psychiatry, 35*, 1273-1287. http://dx.doi.org/10.1111/j.1469-7610.1994.tb01234.x

Rhoades, R.A., Scarpa, A., & Salley, B (2007). The importance of physician knowledge of autism spectrum disorder: results of a parent survey. *BMC Pediatrics,7*(37), 1-10. http://dx.doi.org/10.1186/1471-2431-7-37

Roberts, E. M., English, P. B., Grether, J. K., Windham, G. C., Somberg, L., & Wolff, C. (2007). Maternal residence near agricultural pesticide applications and autism spectrum disorders among children in the California central valley. *Environmental Health Perspectives, 115*, 1482-1489. http://dx.doi.org/10.1289/ehp.10168

Salkind, N.J. (2010). Encyclopedia of research design. Inclusion criteria. Retrieved from http://srmo.sagepub.com/view/encyc-of-research-design/n183.xml

Sansosti, F. J., Lavik, K. B., & Sansosti, J. M. (2012). Family experiences through the autism diagnostic process. *Focus on Autism and Other Developmental Disabilities, 27*(2), 81-92. http://dx.doi.org/10.1177/1088357612446860.

Siegel, B. (1996). *The world of the autistic child: Understanding and treating autism spectrum disorders*. New York, NY: Oxford University Press.

Sices, L., Feudtner, C., McLaughlin, J., Drotar, D., & Williams, M. (2003). How do primary care physicians identify young children with developmental delays? A national survey. *Journal of Developmental & Behavioral Pediatrics*, *24,* 409-417.

http://dx.doi.org/10.1097/00004703-200312000-00002

Siklos, S., & Kerns, K. A. (2006). Assessing need for social support in parents of children with autism and Down syndrome. *Journal of Autism and Developmental Disorders, 36*, 921-933. http://dx.doi.org/10.1097/00004703-200312000-00002

Skellern, C, McDowell, M, & Schluter, P. (2005). Diagnosis of autistic spectrum disorders in Queensland: Variations in practice. *Journal of Paediatrics and Child Health,* 41, 413-419. http://dx.doi.org/10.1111/j.1440-1754.2005.00667.x

Sloper, P. & Turner, S. (1993). Determinants of parental satisfaction with disclosure of disability. *Developmental Medicine and Child Neurology, 35*, 816–825. http://dx.doi.org/10.1111/j.1469-8749.1993.tb11733.x

Smith, T. (1999). Outcome of early intervention for children with autism. *Clinical Psychology: Science and Practice, 6*, 33–49. http://dx.doi.org/10.1093/clipsy.6.1.33

Smith, B., Chung, M. C., & Vostanis, P. (1994). The path to care in autism: Is it better now? *Journal of Autism and Developmental Disorders, 24*, 551-564. http://dx.doi.org/10.1007/bf02172137

Smith, T., Groen, A., & Wynn, J. W. (2000). Randomized trial of intensive early intervention for children with pervasive developmental disorder. *American Journal of Mental Retardation,105*, 269–285. http://dx.doi.org/10.1002/9780470755778.ch6

Spence, S. J. (2004). The genetics of autism. *Seminars in Pediatric Neurology, 11*(3), 196-204. http://dx.doi.org/10.1007/978-0-387-76727-7_27

Standards and Guidelines for the assessment and diagnosis of young children with Autism Spectrum Disorder in British Columbia. (2003). *An evidence-based report prepared for The British Columbia Ministry of Health Planning*. Retrieved from http://www.health.gov.bc.ca/library/publications/year/2003/asd_standards_0318.pdf

Schuntermann, P. (2002). Pervasive developmental disorder and parental adaptation: reviewing and reviewing atypical development with parents in child psychiatric consultation, *Harvard Review of Psychiatry 10*: 16–27. http://dx.doi.org/10.1093/hrp/10.1.16

Taanila, A., Syrjala, L., Kokkonen, J., Jarvelin, M.R. (2002). Coping of parents with physically and/or intellectually disabled children. *Child: Care, Health and Development, 28*(1)*,* 73-86. http://dx.doi.org/10.1046/j.1365-2214.2002.00244.x.

Turner, S., & Sloper, P. (1992). Paediatrician's practice in disclosure and follow-up of severe physical disability in young children. *Developmental Medicine and Child Neurology, 34*, 348-358. http://dx.doi.org/10.1111/j.1469-8749.1992.tb11439.x

University of California Davis Mind Institute. (2015). *Early Start Lab*. Retrieved from http://www.ucdmc.ucdavis.edu/mindinstitute/research/esdm/

U.S. Department of Education. (2105). *IDEA 2004: Building the legacy part c (birth - 2 years old)*. Retrieved from http://idea.ed.gov/part-c/search/new

Vagias, W. M. (2006). Likert-type scale response anchors. Clemson, SC: Clemson International Institute for Tourism & Research Development, Department of Parks, Recreation and Tourism Management.

Warren, Z., McPheeters, M.L., Sathe, N., Foss-Feig, J.H., Glasser, A., . . . Vanderweele, J. (2011). A systematic review of early intensive intervention for autism spectrum disorders. *Pediatrics, 127,* e1303-e.1311. http://dx.doi.org/10.1542/peds.2011-0426

Werner, E., Dawson, G., Munson, J., & Osterling, J. (2005). Variation in early developmental course in autism and its relation with behavioral outcome at 3-4 years of age. *Journal of Autism and Developmental Disorders, 35*, 337–350. http://dx.doi.org/10.1007/s10803-005-3301-6

Wiggins, L. D., Daio, J., & Rice, C. (2006). Examination of the time between first evaluation and first autism spectrum diagnosis in a population-based sample. *Journal of Developmental & Behavioral Pediatrics 27*, 79–87. http://dx.doi.org/10.1097/00004703-200604002-00005

Whiteley, P., Rodgers, J., & Shattock, P. (1998). Clinical features associated with autism: observations of symptoms outside the diagnostic boundaries of autism spectrum disorders. Autism, 2, 145-422. http://dx.doi.org/10.1007/s10803-005-3301-6

Wildman, H.E. (2006). *The health belief model and prediction of parents' choices of autism treatment.* The ASA's 37th National Conference on Autism Spectrum Disorders (July 13-15, 2006). Recorded presentation.

Wing, L. (1988). The continuum of autistic characteristics. In E. Schopler, & G. B. Mesibov (Eds.), *Diagnosis and assessment in autism* (pp. 54-71). New York, NY: Plenum Press.

Wordpress (2011). *Advantages and disadvantages of quantitative research*. Retrieved from http://picardsflute.wordpress.com/2011/01/12/advantages-and-disadvantages-of-quantitative-research/

Appendix A: Demographic Questionnaire

Demographic Information

Please complete this demographic section of the survey. It is important that you answer each question carefully and accurately. No personal information will be revealed in the study results.

Information About the Parent

1. What is your relation to the child?
   ___ Mother
   ___ Father
   ___ Step Mother
   ___ Step Father
   ___ Adoptive Mother
   ___ Adoptive Father
   ___ Legal Guardian
   ___ Other Care Taker/Relative (please specify___________________________)

2. What is your age? _________

3. What is your marital status?
   ___ Married
   ___ Single
   ___ Divorced
   ___ Never Married
   ___ Common-Law
   ___ Separated
   ___ Widowed

4. What is your race/ethnicity? (optional)
   ___ Caucasian
   ___ Asian (Chinese, Japanese, Korean)
   ___ Indo Canadian (Punjabi, Hindi)
   ___ Muslim
   ___ Native
   ___ Latino, Hispanic
   ___ European
   ___ African American
   ___ Philipino
   ___ Other (please specify __________________________________)

5. What is your highest level of completed education?
   ___ Elementary school (6th grade or less)
   ___ Partial junior high school (7th grade through 9th grade)

___ Partial high school (10th grade through partial 12th grade)
___ High school graduate
___ Partial college training
___ College graduate (degree obtained)
___ Partial graduate or professional training
___ Graduate or professional training

6. Which of the following is closest to your annual household income?
   ___ Under $20,000
   ___ $20,000 - $39,999
   ___ $40,000 - $59,999
   ___ $60,000 – $79,999
   ___ $80,000 - $99,999
   ___ $100,000 - $119,000
   ___ $120, 000-$139,000
   ___ $149, 000 and above

7. What city in BC do you currently reside? ___________________________________

Information About Child

8. How old is your child?
   _________ years
   _________ months

9. What is your child's gender?
   ___ Male
   ___ Female

10. What level of education has your child completed?
   ___ None
   ___ Preschool
   ___ Kindergarten
   ___ Elementary School (specify highest grade completed ____)
   ___ Middle School (specify highest grade completed ____)
   ___ Home schooling (specify highest grade completed ____)

Information on Assessment and Diagnosis

11. Did you choose to get your child diagnosed through the BCAAN Network or through a private clinic?
   ___ BCAAN Network ___ Private clinic

12. If you obtained a diagnosis through the BCAAN Network, please specify the location and name of the clinic (Sunnyhill Hospital, contracted BCAAN agency)
   ____

13. If you obtained a diagnosis through a private clinic, please specify the location and name of the clinic ____

14. How long did you wait on a waitlist to obtain a diagnosis? ____ months

15. What is your child's current diagnosis?
    ___ Autism Spectrum Disorder
    ___ Asperger's Disorder
    ___ Childhood Disintegrative Disorder
    ___ Rett's Syndrome
    ___ Pervasive Developmental Disorder – Not Otherwise Specified (PDD-NOS)
    ___ Other (please specify ___________________________)

16. Does your child have any secondary diagnosis or comorbid disorders? Check all that apply.
    ___ Anxiety Disorder
    ___ Attention Deficit Hyperactive Disorder (ADHD) or Attention Deficit Disorder (ADD)
    ___ Mental Retardation
    ___ Obsessive Compulsive Disorder (OCD)
    ___ Sensory Processing Disorder
    ___ Depression
    ___ Schizophrenia
    ___ Hearing Impairment
    ___ Vision Impairment
    ___ Seizures
    ___ Dietary allergies (please specify _____________________________)
    ___ Digestive Problems (constipation, diarrhea, bloating, or abdominal pain)
    ___ Medical issues (epilepsy, heart defects etc.)
    ___ None
    ___ Other (please specify _______________________________________)

17. How old was your child when he/she got the diagnosis?
    ___ years
    ___ months

18. Have any of the child's siblings been diagnosed with Autism Spectrum Disorder?
    ___ yes (if yes, please specify which disorder:_________________________)
    ___ no

Appendix B: Parent Perception Questionnaire

Parent Perception Questionnaire

Before the assessment

1. You were well informed about the assessment service before you attended the first appointment.
    - Strongly disagree
    - Disagree
    - Neither agree nor disagree
    - Agree
    - Strongly agree

2. You were given information describing the assessment process prior to the appointment.
    - Strongly disagree
    - Disagree
    - Neither agree nor disagree
    - Agree
    - Strongly agree

3. The following would have been helpful before seeing the clinician: name and profession, questions to be asked, time it would take to get the diagnosis, different parts of the assessment process.
    - Strongly disagree
    - Disagree
    - Neither agree nor disagree
    - Agree
    - Strongly agree

4. You knew the name and professional background of the clinician prior to attendance.
    - Strongly disagree
    - Disagree
    - Neither agree nor disagree
    - Agree
    - Strongly agree

5. If you did not know the name and professional background you have liked to have known.
   - Strongly disagree
   - Disagree
   - Neither agree nor disagree
   - Agree
   - Strongly agree

The Assessment Process

6. It was easy and convenient getting into an assessment (waitlist).
   - Strongly disagree
   - Disagree
   - Neither agree nor disagree
   - Agree
   - Strongly agree

7. The professional listened carefully to you.
   - Strongly disagree
   - Disagree
   - Neither agree nor disagree
   - Agree
   - Strongly agree

8. You had trust and confidence in the professional you saw.
   - Strongly disagree
   - Disagree
   - Neither agree nor disagree
   - Agree
   - Strongly agree

9. You treated with trust and dignity.
   - Strongly disagree
   - Disagree
   - Neither agree nor disagree
   - Agree
   - Strongly agree

10. You were given enough time to discuss your concerns about your child.
    - Strongly disagree
    - Disagree
    - Neither agree nor disagree
    - Agree
    - Strongly agree

11. The communication could have been done differently.
    - Strongly disagree
    - Disagree
    - Neither agree nor disagree
    - Agree
    - Strongly agree

12. After the first meeting you would have liked a letter with the plan for further assessment and appointment dates.
    - Strongly disagree
    - Disagree
    - Neither agree nor disagree
    - Agree
    - Strongly agree

13. You were given the opportunity to provide feedback at the time of the assessment.
    - Strongly disagree
    - Disagree
    - Neither agree nor disagree
    - Agree
    - Strongly agree

14. The assessment process was satisfactory.
    - Strongly disagree
    - Disagree
    - Neither agree nor disagree
    - Agree
    - Strongly agree

15. There were parts of the assessment process you would have liked to have been done differently.
    - Strongly disagree
    - Disagree
    - Neither agree nor disagree

Agree
Strongly agree

The Outcome of the Assessment

16. At the end of the assessment you had enough information regarding the assessment process.
    Strongly disagree
    Disagree
    Neither agree nor disagree
    Agree
    Strongly agree

17. The assessment outcome was effectively communicated verbally and through written means.
    Strongly disagree
    Disagree
    Neither agree nor disagree
    Agree
    Strongly agree

    ***Please check which one**
    Verbally only
    Written only
    Written and verbal

18. The assessment could have been communicated differently.
    Strongly disagree
    Disagree
    Neither agree nor disagree
    Agree
    Strongly agree

19. At the end of the assessment you were given or posted an assessment report.
    Strongly disagree
    Disagree
    Neither agree nor disagree
    Agree
    Strongly agree

20. You understand the report.
    - Strongly disagree
    - Disagree
    - Neither agree nor disagree
    - Agree
    - Strongly agree

21. The report contained an initial page with the outcome of the assessment clearly documented.
    - Strongly disagree
    - Disagree
    - Neither agree nor disagree
    - Agree
    - Strongly agree

22. You were able to discuss the report at the next appointment.
    - Strongly disagree
    - Disagree
    - Neither agree nor disagree
    - Agree
    - Strongly agree

23. You had a say in what information the report should contain.
    - Strongly disagree
    - Disagree
    - Neither agree nor disagree
    - Agree
    - Strongly agree

24. You were given a chance to ask questions either in the feedback meeting or the following meeting.
    - Strongly disagree
    - Disagree
    - Neither agree nor disagree
    - Agree
    - Strongly agree

25. You received additional information regarding your child’s condition at the end of the assessment either verbally, written, or brochures.
    - Strongly disagree
    - Disagree
    - Neither agree nor disagree

Agree
Strongly agree

26. If a certain behavior consultant or agency was recommended to you, you were happy for your child to be referred to the service?
    Strongly disagree
    Disagree
    Neither agree nor disagree
    Agree
    Strongly agree

27. You felt as if you received enough information about the condition itself and future appropriate interventions in BC related to Autism.
    Strongly disagree
    Disagree
    Neither agree nor disagree
    Agree
    Strongly agree

28. You were given the opportunity to watch a video about the condition following diagnosis.
    Strongly disagree
    Disagree
    Neither agree nor disagree
    Agree
    Strongly agree

Appendix C: Participant Consent Form

Parental Perceptions of the Diagnostic Process for Autism Spectrum Disorder: a Comparison Between Private diagnosis and Government Funded Diagnosis in British Columbia

You are invited to take part in a study that examines the parental perceptions of families who receive a diagnosis of Autism Spectrum Disorder (ASD) in British Columbia. You were invited to participate in this study because you might fall within the inclusion category of having a children with autism under the age of 6 and diagnosed in BC. Please read this form and ask the researcher any questions you might have before making the decision to participate.

This study is conducted by Ramen Saggu, a doctoral candidate at Walden University.

Background Information:

The purpose of this study is to examine parental perceptions of the ASD process in BC across the two routes of obtaining a diagnosis, the government funded BCAAN network and the private diagnosis process.

Procedures:

If you agree to participate in this study, you will be asked to complete a demographics questionnaire and one survey. This should take approximately 20-30 minutes.

Voluntary Nature of the Study:

Your participation in this study is completely voluntary. You may withdraw consent to participate in this study at any time.

Risks and Benefits of Being in the Study:

There are no risks to taking part in this study other than the time it will take to participate in completing the surveys and recalling past feelings of receiving the ASD diagnosis. If you experience significant distress you can discontinue at any time. The apparent benefits to participating in this study are that valuable information will be provided by completing this research. This information can contribute to improving the ASD diagnosis process for families in BC by increasing efforts to improve professional-parents interactions and diagnosticians offering more support on ASD treatment to parents of children diagnosed with ASD.

Compensation:

There will be no compensation to take part in this study.

Confidentiality:

The records of this study will remain confidential. In case of any portions of this research being published, no identifying information will be included. Research records will be kept in a locked file, and can only be accessed by the researcher. You will not have to sign your name or provide any identifying information. By completing the study, your consent is implied. Please feel free to retain a copy of this consent form.

Contacts and Questions:

Researcher:
Ramen Saggu

Walden representative whom you can contact in case of questions about your rights as a participant:

Dr. Cheryl Tyler-Balkcom

Statement of Consent:

I have read the above information. If I had questions I was able to ask the researcher and receive adequate answers. I consent to participate in this study. The completion of this study implies my consent.

Your participation in taking part in this study is appreciated.

Appendix D: Manchester Audit Tool Permission

Central Manchester University Hospitals NHS
NHS Foundation Trust

North CAMHS
The Bridge, Unit C
Madison Place
Northampton Road
Manchester Central Park
Manchester
M40 5BP

Tel: 0161 203 3260
Fax: 0161 203 3253

Our Ref : MNCM/LW
30th January 2014

TO WHOM IT MAY CONCERN

Ramen Saggu has my permission to use and adapt the survey as published in Parental Perceptions; A Manchester Service for Autism Spectrum Disorders by Mischa Mockett, Jamila Khan, and Louise Theodosiou.

M. Mockett
Signed:……………………………….
Dr. Mischa N C Mockett
Consultant Child & Adolescent Psychiatrist