Understanding Parent Perceptions of Autism Spectrum Disorder Diagnosis and Intervention Services Through A Culturally Responsive Framework

Kristina Donald

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By: Kristina Donald

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Signed by the final examining committee:

Dr. Nina Howe__________________________ Chair

Dr. Miranda D'Amico____________________ Examiner

Dr. Diane Pesco_________________________ Examiner

Dr. Harriet Petrakos______________________ Supervisor

Approved by ____
Chair of Department or Graduate Program Director

____
Dean of Faculty

Date ____

Abstract

Understanding Parent Perceptions of Autism Spectrum Disorder Diagnosis and Intervention Services Through A Culturally Responsive Framework

Kristina Donald

While the process of obtaining an Autism Spectrum Disorder (ASD) diagnosis for a child can involve several challenges for parents (Keenan, Dillenburger, Doherty, Byrne, & Gallagher, 2010), this process may be even more complex for immigrant parents (Begeer, El Bouk, Boussaid, Terwogt, & Koot, 2009; Jegatheesan, Fowler, & Miller, 2010). This qualitative study utilized an eco-cultural framework (Super & Harkness, 1986) to explore the experiences of eight immigrant families during their process of obtaining a diagnosis and services for their children with ASD. Each family participated in two in-depth, semi-structured interviews (45-90 minutes) with many open-ended questions to permit parents to recount their story of obtaining the ASD diagnosis and services for their children. Using open and axial coding, the data were analyzed inductively and deductively to reveal various themes related to the diagnosis, treatment services, relationships with professionals, and future expectations for their children. Given that Montreal is such a highly multicultural metropolis (Statistics Canada, 2007), it is important that professionals recognize how parental beliefs about the ASD diagnosis could shape their treatment decisions and adherence (Dale, Jahoda, & Knott, 2006). Data from this qualitative study support the importance of adopting a culturally responsive practice when working with families by considering families' perceptions and the core meaning of their experiences (Harry, 2002). That is, a culturally responsive practice helps to ensure that parents are given a voice, permits professionals to understand how parent perceptions may be formed, and allows for professionals to revisit any relevant problems that may interfere with parents' negotiation of services.

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Table of Contents

List of Tables

List of Appendices

Understanding Parent Perceptions of Autism Spectrum Disorder Diagnosis and Intervention Services Through A Culturally Responsive Framework

Obtaining an Autism Spectrum Disorder (ASD) diagnosis for a child can be a stressful, long, and confusing process for many parents (Keenan, Dillenburger, Doherty, Byrne, & Gallagher, 2010). Unfortunately, the challenges that parents experienced during the diagnosis continue with the process of finding, selecting, and obtaining services for their children (Keenan et al., 2010). An important consideration, which may impact the diagnostic and intervention processes, is that parents hold vast differences in their beliefs about child development, disabilities, as well as having unique methods of coping and accessing information (Harry, 2002). Many parents, however, believe that professionals do not adequately consider their beliefs and perceptions about the diagnosis, and their child, and as a result report negative perceptions of the diagnostic process and intervention services (e.g., Ennis-Cole, Durodoye, & Harris, 2013; Kennan et al., 2010; Osbourne & Reed, 2008). For immigrant parents, these processes can be even more complex due to language barriers, lack of an adequate support network (Jegatheesan, Fowler, & Miller, 2010), and ethnic bias within the diagnostic process (Begeer, El Bouk, Boussaid, Terwogt, & Koot, 2009). By adopting a culturally responsive practice, professionals could respond to the challenges that parents undergo during the process of obtaining a diagnosis and services for their children with ASD (Harry, 2002). Naturally, professionals may understand parents' experiences, beliefs, and perceptions after an examination of the contextual variables present in the microenvironment of the child and family (Super & Harkness, 1986). This could, in turn, improve their practice in helping families care for their children with ASD. The present study, therefore, utilized a phenomenological approach to explore and generate meaning of the experiences of parents of children with ASD during the process of diagnosis as well as selecting and receiving treatment services, using an eco-cultural framework.

Review of the Literature

ASD and Prevalence

Autism Spectrum Disorder (ASD) is a lifelong neurodevelopmental disorder that is characterized by deficits in communication, social-emotional functioning, and by the presence of stereotyped patterns of behavior (American Psychiatric Association [APA], 2013). An ASD diagnosis can be distressing for parents as there is no consensus on the cause or cure of the disorder. Furthermore, it can be challenging to determine an accurate prognosis, as numerous factors must be considered, such as the severity of language impairment and the presence or absence of an intellectual disability (APA, 2013). While research attempts to fill in the gaps of our knowledge on how to understand and provide support and interventions for children with this disorder (Ratajczak, 2011), the prevalence of ASD continues to grow (Centers for Disease Control and Prevention [CDC], 2014), thus increasing the importance of conducting research on issues related to ASD services for children and families, in order to better inform and support families raising a child with ASD.

The most recent autism prevalence rates are estimated to be as high as 1 in 68, as per a study conducted in 11 U.S. states (CDC, 2014). In Canada, the National Epidemiologic Database for the Study of Autism in Canada (NEDSAC) looked at the rates in four regions, between 2003 and 2010 and observed an increase in ASD prevalence rates across all four areas, for all age groups between 2 and 12-years-old (NEDSAC report, 2012). More locally, in a Montreal study conducted in 2003 and 2004, prevalence rates of Pervasive Developmental Disorders (PDDs) were estimated through an examination of school records from the Lester B. Pearson School Board (LBPSB) across Kindergarten to grade 11 (Fombonne, Zaharian, Bennett, Meng, & McLean-Heywood, 2006). The survey revealed a prevalence of 64.9 per 10,000 and an increasing trend in prevalence for the younger grades, suggesting as much as a 10% annual increase in prevalence rate. A later study confirmed these findings, surveying the records of all students, Kindergarten to grade 11, in the English Montreal School Board (EMSB) between 2007 and 2008 (Lazoff, Zhong, Piperni, & Fombonne, 2010). According to the EMSB records surveyed for this study, prevalence of PDD was estimated at 79.1/10 000. Similar to the results reported by Fombonne and colleagues (2006), the prevalence was higher for the younger grades and was estimated to have an annual increase of 17% (Lazoff et al., 2010).

Factors Affecting the ASD Prevalence Rate

Age of diagnosis. One possible reason for the higher increase in prevalence for the later birth cohorts could be that improved diagnostic assessment methods have led to children being diagnosed at an earlier age. Ouelette-Kuntz and colleagues (2009) surveyed diagnostic records between 1997 and 2005 of 769 children, in four regions of Canada (Manitoba, Ontario, Prince-Edward Island, and Newfoundland & Labrador) and found that the age of children being diagnosed varied across regions. The highest median age of ASD diagnosis was 47-months in the southeastern Ontario region and the lowest median age was 36-months in the Newfoundland and Labrador region. A later study reviewed the diagnostic records of 2180 children and revealed the average age of diagnosis, across six regions in Canada (British Columbia, Alberta, Manitoba, southeastern Ontario, Prince Edward Island, and Newfoundland and Labrador) was 60.8-months (Coo et al., 2012). This result resembles the average age of diagnosis of ASD in Quebec, which is approximately 69.6-months, as reported in a study on the diagnostic process in Quebec (Poirier & Goupil, 2008b). Coo and colleagues (2012) conducted further analyses, to detect variations in age of diagnosis as a result of individual and family characteristics. This study revealed that age of diagnosis was significantly associated with diagnostic type, birthplace, and having a sibling with ASD. More specifically, later age of diagnosis was associated with PDD-NOS, Asperger syndrome, and a foreign birthplace, while an earlier diagnosis was associated with autistic disorder, being born in Canada, and having a sibling with an ASD diagnosis.

Ethnicity. Early diagnosis of ASD symptoms is not as common across ethnic minorities. The finding that immigrant children may be diagnosed at a later age was examined in a Dutch study conducted by Begeer and colleagues (2009). The authors first looked at the proportion of ethnic minorities in ASD institutions and confirmed that there was an under-representation of minority groups in Dutch ASD institutions. Secondly, the authors explored ethnic bias in ASD diagnosis by presenting six case vignettes, of differing ethnic backgrounds, to 82 pediatricians. The vignettes described the age, developmental level, familial circumstances, and day-to-day issues of a young boy. Results revealed that in comparison to majority groups, the pediatricians were less likely to diagnose ASD for minority groups. Begeer et al. (2009) concluded that this was evidence of an ethnic bias among pediatricians and may be a contributing factor to the under-representation of minority groups in Dutch ASD institutions. The authors explained this bias by proposing that pediatricians may be more inclined to hold back on an ASD diagnosis because they attribute the delays in social and communication functioning to issues of adjusting to the majority culture and language. Mandell and colleagues (2009) reported similar findings following their review of the evaluation records of 2568 8-year-old children, who were under the surveillance of the Autism and Developmental Disabilities Monitoring (ADDM) network. More specifically, Mandell et al. (2009) concluded that compared to White children, Black and Hispanic children were less likely to be diagnosed with ASD. The results of these studies are concerning as it could indicate that children belonging to ethnic minority groups may not have the same opportunity to access treatment at an early age as compared to children of the majority group. Norbury and Sparks (2013) reviewed the literature on the diagnostic process and highlighted some inherent problems, such as the diagnosis relies on behavioral assessments where interpretations of behaviors may be influenced by cultural perceptions and values. The authors suggested adopting a culturally appropriate assessment practice by considering the unique cultural context of a family and by reviewing the cross-cultural research on ASD diagnostic processes.

While there is some evidence suggesting that age of diagnosis may vary (e.g., Coo et al., 2012), it is unclear if there is sufficient evidence for variations in ASD prevalence rates across cultures and countries. In a systematic review of recent international epidemiological studies, no major differences were found between the increasing trend in prevalence rates across socioeconomic, cultural/ethnic, and geographic variables (Elsabbagh et al., 2012). Even as the prevalence rates varied across region, the authors concluded that it was simply due to the lack of available data in some countries and thus this did not provide sufficient evidence to claim that factors such as socioeconomic, cultural/ethnic, and geographic variables could affect the prevalence rate.

The results of other epidemiological studies, however, suggest differences in prevalence rates across racial and cultural variables (CDC, 2012; Yu, Huang, & Kogan, 2008). In the U.S., for example, the reported prevalence of White children diagnosed with ASD, as compared to other visible minorities, was greater (CDC, 2012). The finding that immigrant families may experience different access to, and care from, local services has also been suggested by research on general health services in the U.S. Yu and colleagues (2008) examined 12, 400 families' access to health care through survey data collected across 6 states with the highest proportion of immigrants in the country. The findings revealed that immigrant families experienced less access to health care than to U.S. born families; however considerable variation in healthcare access among immigrant families were noted across states, due to their unique policies, services, and resources. The authors concluded, therefore, that access to health care for immigrant families was directly linked to state policies and programs, thus highlighting the need to reform policy and practice to accommodate and encourage immigrant families to utilize healthcare services.

Thus, there seems to be a lack of consensus in the literature on the factors affecting the prevalence rates of ASD for immigrant families and the potential bias of diagnosis and access to health services for ethnically diverse groups. This justifies the need to explore the personal experiences of immigrant families who are seeking assessment for an ASD diagnosis, and subsequently, ASD services for their child. Furthermore, research suggests that immigrant families may not access and use general health services as frequently as non-immigrant families (Yu et al., 2008), which may contribute to a difficult path to obtaining a diagnosis for their child. Understanding parents' journey of evaluation and diagnosis and the meanings they attribute to it can provide context to their experiences of later accessing services and subsequently forming relationships with professionals.

Parents' Experience with ASD Diagnosis

Diagnostic process. The diagnostic process can be a long and frustrating burden for parents. For some, the process begins with simply trying to get their concerns about their child's behavior or development heard by a physician. In general, parents have reported it was difficult to get a physician to take their concerns seriously and in one case study, a final diagnosis of ASD was only made when the child was 13-years-old (Glazzard & Overall, 2012). Diagnoses at a later age could also be due to long wait lists, or when a child has another disorder (i.e., comorbidity), thus making the identification of ASD symptoms more challenging (Glazzard & Overall, 2012). Unfortunately, even once a diagnosis is complete, the challenging process of understanding, gaining information, and accessing services commences and will continue well beyond the initial stage of diagnosis (Mulligan, MacCulloch, Good, & Nicholas, 2012).

Several studies have reported that parents experienced difficulties in understanding the initial diagnosis because there was a lack of information provided to them during the initial diagnosis about the disorder, prognosis, and appropriate services (Keenan et al., 2010). In this light, parents also reported a complete lack of follow up meetings and continuity of service following the final diagnosis (Mulligan et al., 2012). When asked what parents would have wanted to see improved, several parents reported that they would have wanted practical information about what to expect from their child, or what impact the diagnosis would have on their family (Osborne & Reed, 2008).

Similar findings were reported from a Quebec study on the diagnostic process. Poirier and Goupil (2008a) recruited 88 parents of children with ASD who completed a questionnaire on their experiences and perceptions of the diagnostic process in Quebec. Most parents reported that they lacked important information, such as a general description of ASD and available treatment services and some families even requested that the information given be clearer and less technical. Other parents reported wanting more support, such as psychological or parent group meetings to deal with the initial challenges of learning that their child had an ASD. Consistent with other studies (e.g., Mulligan et al., 2012), parents would have liked further follow-up meetings to ask questions and obtain more information after having had a chance to process the information given at the diagnostic meeting (Poirier & Goupil, 2008a).

Parent reactions to the diagnosis. Some of the most common reactions from parents when they receive the final diagnosis include shock, sadness, and feeling overwhelmed (Glazzard & Overall, 2012). Casey and colleagues (2012) administered a survey to 265 parents of children with autism and found that approximately 20% of the parents in their sample reported moderate to severe Posttraumatic Stress Symptoms (PTSS) during the time of their child’s diagnosis. Parents also reported high levels of stress as a result of dealing with a number of professionals and with the challenges of forming collaborative relationships with them (Moh & Magiati, 2012). In some cases, however, parents reported relief that their concerns about their child's difficulties were valid (Osborne & Reed, 2008). Such differences in reactions would be expected considering the unique nature of parents' perceptions, expectations, and beliefs about their children's development. It seems that social, psychological, and cultural influences may play a role in how families experience and perceive the diagnostic process.

Super and Harkness (1986) propose an eco-cultural theory that examines families' social, psychological, and cultural dimensions. The authors considered both anthropological and psychological perspectives of child development to form the developmental niche framework for understanding the processes of development within the child's microenvironment. The developmental niche framework facilitates understanding and analyzing, cross-culturally, how culture structures the early childhood environment and how this influences child development. More specifically, they examined three main systems: (a) physical setting, (b) customs of care, and (c) psychology of the caretaker. The physical setting encompasses the actual location, condition of the home, daily activities, as well as the people present and social roles that make up the child's social environment. The customs of care refer to the roles and customs that caretakers use to protect, educate, and prepare their child for adult life as appropriate to the physical and social setting. The psychology of the caretaker includes the beliefs, values and emotional functioning of the caretakers, as well as ethnotheories about the needs of children, the nature of development, and the customs of care. The three subsystems of the developmental niche are interconnected and have a common goal; to mediate the development of the child (Harkness et al., 2007), as in Brofenbrenner's ecological system theory (Brofenbrenner, 1979). As such, when a parent learns of an ASD diagnosis for their child, several of the systems may be activated or disturbed. To meet the developmental and individual needs of the child, parents must be able to facilitate coordination between these systems (Harkness et al., 2007). For example, learning that a child has a disability may force a parent to revisit the customs of care common to their culture and to adopt different roles of caring for the child, such as taking on an educator role or a more protective role than was commonly expected in their culture (Harkness et al., 2007). In addition, parents may access a variety of settings to provide this care and may themselves be questioned about their parenting practices. This may further impact how parents perceive their roles and the formal and informal support systems around them. Additionally, immigrant parents have to navigate these developmental issues while adapting to a new country and culture (Jegatheesan et al., 2010).

Considering the many challenges that the diagnostic process can present, both in dealing with the health system and in understanding and coping with the diagnosis, parents may well become frustrated and unsatisfied with the process (e.g., Mulligan et al., 2012). Even more so for immigrant parents who may be facing the hardships of navigating the health system to obtain a diagnosis, to understand its implications, and to find resources with little or no support, which can leave immigrant parents with an overall negative perception of the diagnostic process (e.g., Jegatheesan et al., 2010; Keenan et al., 2010). In fact, parents have reported that these challenging and negative experiences have resulted in a pattern of mistrust of professionals (Stoner et al., 2005). These findings are concerning, as successful parent and professional collaboration is an important element to effective intervention programs (Steiner, Keogel, Keogel, & Ence, 2012).

Beliefs and Perceptions of ASD

Following the diagnosis, parents begin the journey of learning about ASD and forming their own beliefs and perceptions about its cause, effects, and prognosis. By examining this process through the framework of the developmental niche, it is evident that beliefs and perceptions are strongly influenced by the cultural context of the child (Super & Harkness, 1986). The physical setting, customs of care, and psychology of the caretaker each play a role in understanding their child's ASD diagnosis. These three subsystems work together and when there is a change in one, it affects the coordination of the other systems. The diagnosis may introduce a change in the parenting role and that may affect change in other components of the system (e.g., how to parent a child with special needs, or how to cope with the diagnosis). It is therefore not surprising that studies have revealed a wide range of perceptions and beliefs on the cause, treatment, and prognosis of ASD across individual parents. Herbert and Koulouglioti (2010) conducted a review of the literature on parents' beliefs of ASD and found that parents held a wide range of beliefs on the cause of their children's ASD. In addition, the age of the diagnosis seemed to play an important role. For example, parents who reported that their child had difficulties from birth were more likely to ascribe genetic or heredity issues as causal factors, whereas parents who reported a regression in their child's development were more likely to attribute environmental factors as the cause of their child's ASD.

In their study, Dale, Johoda, and Knott (2006) were interested in mothers' beliefs as to the cause of ASD. Therefore, they conducted a focus group and semi-structured interviews with 16 Scottish mothers of children with ASD. The focus group methodology was an effective way to understand the perceptions of parents in a group discussion; these groups provided parents with an opportunity to discuss and share similar issues surrounding their children's diagnosis, as they felt supported by other parents when they were discussing their challenges and beliefs about parenting their child with ASD. In addition, individual interviews served to provide mothers with an opportunity to share more in-depth information on topics related to the cause and course of their children's ASD. More specifically, the authors analyzed mothers' attributions of the diagnosis using Weiner's dimensions of locus of cause, stability, and controllability. Overall, mothers' beliefs ranged from genetic causes to environmental causes, such as immunizations. Furthermore, the authors concluded that mothers' beliefs about the cause of ASD were linked to their beliefs about the treatment of ASD. For example, mothers who believed the cause to be biological would tend to view biological treatments, such as following a gluten-free diet to be effective, whereas mothers who believed that the causes were environmental would limit or avoid future immunizations for their children. Mothers' beliefs also varied with regard to the course of their child's development with ASD. Some mothers described beliefs that the condition was stable and the difficulties would persist into adulthood, whereas several mothers believed that the condition might be overcome either by simply maturing naturally, or by following the latest research treatments.

In a recent U.S. study, 11 parents participated in two focus groups to discuss their views on parenting a child with ASD. Several parents felt that the public and extended family members lacked understanding of the disorder and attributed the children's behavioral difficulties to poor parenting, which could leave parents feeling isolated and alone in supporting their children (Neely-Barnes, Hall, Roberts, & Graff, 2011). Beliefs about how to deal with feeling blamed for their children's disorder varied across parents and included various ways of dealing with these issues. For example, some parents felt that their role was to educate the public by increasing their presence and participation in the community, and to confront people on their misunderstandings of the disorder; other parents ignored the public's negative reactions to their children and did not disclose the diagnosis.

These differences in beliefs and perceptions about the course and cause of ASD may present a challenge to parents who are faced with a new diagnosis, thus necessitating a remarkable need to adjust to this change. In addition, parents' new ethnotheories about development and parenting may be further challenged by their own individual and familial cultural views of parenting and expectations of child development. Therefore, the customs of care, the physical and social setting, and the psychology of the caretakers regarding children with special needs, may vary across families. Indeed, parent's perceptions of ASD can be embedded in the cultural context of particular settings. For example, Korean parents reported associating the disorder with shame and guilt (Kim, 2012) while parents in China described experiencing discrimination and rejection from schools when their children were diagnosed with special needs (McCabe, 2007). Using the phenomenological approach to gain an understanding of the lived experiences and meanings that parents attribute to their experiences, Desai, Divan, Wertz, and Patel (2012) conducted in-depth interviews of 12 parents of children with ASD in India. The inquiry revealed that parents' beliefs about their child's ASD were variable and progressed through phases, such as initially believing the difficulties to be temporary despite the confirmation of an official diagnosis and then recognizing, through social comparison with other children, that the difficulties were persistent and would require specialized care to address.

Families living out of their home country may continue to hold beliefs and perceptions common to their home country. Ravindran and Myers (2012) interviewed 24 Indian parents of children with ASD living abroad, and found that many parents continued to hold some traditional beliefs, such as attributing cause to fate, or to transgressions in a past life. These beliefs, common to those held in their home country, demonstrate the importance of recognizing the different beliefs and perceptions that parents may hold of their child with ASD, despite them being in the same geographic location as others. Similarly, as noted during the time of diagnosis, these beliefs and perceptions are often unknown to professionals working with the children and their parents because a culturally responsive approach to diagnosis is not typically used in the diagnosis of autism (Begeer et al., 2009; Norbury & Sparks, 2013).

Further research is warranted on how parents perceive the diagnosis in order for professionals to adapt their interventions to the families. The current research has utilized qualitative methods to elicit parents' views and these have been analyzed independently of professionals' perceptions, in order to ensure that the focus has been on how parents make meaning of the information they receive from professionals. Further exploration in this area requires the use of a phenomenological approach to describe the unique experiences and meanings that parents attribute to the ASD diagnosis and how they believe this influences their response to interventions.

Autism Treatment

While there are numerous treatments for ASD, they are not all equally supported by empirical research (Green, 2007). Currently, the most supported interventions are programs that involve Applied Behavior Analysis (ABA) (Green, 2007). The term ABA was first coined by Baer, Wolf, and Risley (1968), but is based on the scientific principles of behavior. Although commonly misconceived, ABA is not a particular treatment model, but a scientific approach to increasing socially significant behavior through the application of direct observation, measurement, and functional analysis of the relations between the environment and behavior (Cooper, Heron, & Heward, 2007). More precisely, the science of ABA has seven specific dimensions that serve to differentiate the approach from other disciplines, such as being analytic, behavioral, and technological (Baer et al., 1968). As such, applications of ABA can take on many different forms and be used across a variety of programs, populations, and settings.

One application of ABA principles is Intensive Behavioral Intervention (IBI). IBI is a methodology designed specifically for children with autism. The teacher to child ratio is one to one and the intensity of the teaching is generally between 20 and 40-hours a week. Despite these specifications, IBI will include all other dimensions of ABA, such as making data-based decisions, demonstrating effectiveness through the systematic manipulation of environmental variables, and using procedures derived from basic principles of behavior (Cooper et al., 2007). In Quebec, Rehabilitation Centers for Intellectual Disabilities and Pervasive Developmental Disorders have been mandated to provide children, under the age of 6-years-old, who have a diagnosis of PDD, with a maximum of 20-hours of IBI services a week (Quebec Ministry of Health and Social Services, 2003). Although these services are in place, the reality is that many parents find it challenging to access such government services when their child is at the optimal age to benefit from therapy because of the difficulties of obtaining a diagnosis, lack of coordination among services, and long wait lists for IBI services (Le Protecteur du Citoyen, 2009). As an alternative, parents could access services through the private sector. While private IBI services may be more expensive and thus not possible for some parents, they nevertheless permit families to access services at a more optimal time.

Regardless of whether services obtained are public or private, it is ideal that they commence at an earlier age, around the age of 3-years-old (Barbaro & Dissanayake, 2009). As children do not have to be in school full time until the age of 6-years-old, parents tend to be very involved with supporting and encouraging their children's development during these years. One of the dimensions of ABA is generality, meaning that interventions should produce changes in behavior that are maintained over time, in other environments, and apply to other behaviors (Baer et al., 1968). To achieve this, parent participation and implementation of the intervention procedures are critical. In a review of parent training in ABA programs, it was revealed that there remains little research on best practices for ways to successfully include parents in treatment programs (Steiner et al., 2012). Additionally, some recommendations were made to consider various factors in making parent training and involvement successful, such as alleviating parental stress, respecting parental availability, individualization of the training, and formally training professionals (Steiner et al., 2012).

Parents and ASD Services

Parents' perceptions of ASD services have varied depending on ease of implementation, advice from professionals, and level of commitment. These factors have been found to influence parents' decisions for selecting a particular treatment, as well as their perceptions of its effectiveness (Green, 2007). The roles that parents take on in service can also vary depending on the type and nature of the intervention and may include parents in the role of advocate, supporter, monitor, expert, and case manager (Mulligan et al., 2012; Stoner & Angell, 2006). Parent involvement has been defined in a number of different ways, depending on the focus of the research, however much parent involvement research has been done in the school readiness and school transition literature (e.g., Janus, Lefort, Cameron, & Kopechanski, 2007). Some defining features of parent involvement are communicating with professionals regarding the educational goals and programs, participating in educational activities and events at school, implementing learning strategies and goals at home, and collaborating with professionals in the process of establishing learning goals and programs for their child (Epstein & Dauber, 1991). Solish and Perry (2008) explored the predictors of parent involvement in IBI programs in Ontario by asking 48 parents to respond to questions related to their involvement. Some elements considered as defining parent involvement in this study included directly implementing IBI sessions, applying learning strategies at home to promote generalization, communicating with IBI staff, attending meetings, working collaboratively with professionals to devise learning objectives and goals, and reading relevant literature. In this study, parent self-efficacy was revealed to be the strongest predictor of parental involvement in their child's IBI program. This finding is consistent with the literature on parent involvement in education (e.g., Hoover-Dempsey, Walker, Jones, & Reed, 2002). Other variables that correlated with involvement were knowledge of IBI and belief in IBI services. The authors concluded that increasing parents' confidence in their ability to implement the program and teaching them about IBI to increase their knowledge and belief in its efficacy, could improve their involvement.

Parental involvement was also explored in the government IBI programs in Quebec. Granger, Rivières-Pigeon, Sabourin, and Forget (2012) conducted semi-structured interviews with 13 mothers of children with ASD to learn about the nature of parent involvement in the programs. Various types of involvement were identified by the participants, including active roles, such as organizing educators' schedules, verifying work that was completed, and acting as liaison between all individuals working with their child. Some passive roles included assisting educators with material preparation, attending meetings with the IBI team to learn about child's progress, and being present during IBI sessions, but not participating. None of the mothers reported actively participating in sessions and some described barriers, such as time, feeling that they were disturbing the session, and not being able to cope with their child's diagnosis, as preventing this type of involvement. Other mothers described taking on a more passive role in program involvement and decision making because they viewed the IBI team as experts and thus did not feel the need to contribute. One implication of these findings, as mentioned by the authors, is that IBI program directors could influence the level of parent involvement by addressing some of the barriers that parents may be facing.

Other environmental influences that parents report as barriers to involvement may be related to the cost, accessibility of services, and the time and energy required to deliver interventions (Brookman-Frazee, Baker-Ericzén, Stadnick, & Taylor, 2012; Mackintosh, Goin-Kochel, & Myers, 2012). In keeping with the developmental niche framework, it is important to consider that when there is a change or disruption from the outside (e.g., economic, access to resources) it will influence the role that parents can take in the intervention process. Moes and Frea (2000) explored parent perceptions of and adherence to different intervention approaches, namely prescriptive and contextualized. A prescriptive approach is when the intervention goals and procedures are prescribed by the professional and the contextualized approach is when the intervention is designed by the professional in collaboration with the family to consider the families' unique contextual variables such as daily routines, needs, and resources. In one case, a family, with a 3-year-old boy with ASD, was given the opportunity to experience both treatment approaches, to address their son's disruptive behavior and non-compliance with demands. The prescriptive treatment involved the professional simply dictating to the family that they should be teaching him to ask for a break, or to follow through with the demands using physical guidance if a break was not warranted. The contextualized treatment was created through parent-professional collaboration and took into consideration the parents' goals for intervention and their intervention program preferences. More specifically, the contextualized intervention involved teaching the child to ask for help and included reinforcing the child for completing tasks. The results indicated that a greater reduction of problem behavior and improvement in compliance were observed in the contextualized phase and parents rated the contextualized approach as a more sustainable intervention than the prescriptive one. The authors concluded that an understanding of families' contextual variables, such as daily routines, needs, and beliefs about treatment, should be considered during treatment planning for children with ASD in order for the interventions to be sustained and generalized across settings and situations.

Similarly, Harry (2002) discusses the need for a cultural fit between family and intervention programs, as there can be many difficulties, such as differences in beliefs about disabilities, coping styles, and different access to information that may impact the diagnostic and intervention process. To overcome these challenges, Harry (2002) recommended that professionals obtain specific training in cultural awareness, learn to involve families in the intervention process, and practice on-going program evaluation and modification to adapt to the families' needs. In addition to program planning, intervention, and evaluation, the nature of the parent-professional relationship will be influenced by the perceptions and beliefs professionals hold about families and how families perceive professionals. Considering the parent-professional relationship is also important in ensuring that the intervention program is a good fit for a family.

Parent-Professional Relationship in ASD Treatment Programs

Despite the importance of exploring the parent-professional relationship in ASD intervention programs, limited attention has been given on how differences in perceptions between parents and professionals may be associated with challenges in parent-professional collaboration. In one study, Dillenberger and colleagues (2010) interviewed 95 parents of children with autism and 67 multi-disciplinary professionals on the theme of raising a child with ASD. Through a series of questionnaires and a focus group with parents, the authors revealed differences in perceptions among parents and professionals. For example, professionals seemed to focus on the external problem behaviors as most challenging, such as difficulty sleeping and following daily routines, whereas parents were more focused on the core deficits of the disorder, such as communication and social-emotional problems. Professionals also underestimated the various employment and career restrictions that raising a child with ASD could present. Finally, parents attributed greater importance to more training and resources in ASD education programs than did professionals. The results of the study could provide some insight into why parent-professional relationships may be challenging, including differing perceptions about the experience of raising a child with ASD and the various needs of that child.

In other studies, parents have reported that professionals do not communicate enough, may be disrespectful, and do not permit parents to be real partners (e.g., Hodge & Runswick-

Cole, 2008). More specifically, Mackintosh and colleagues (2012) reported that parents expressed feeling that professionals did not listen to what they had to say about their children's needs, and that developing a partnership was difficult because there was a high turnover of staff and infrequent meetings.

Parents and professionals play different roles, and this may cause problems as they may have different goals for the interventions. In most cases, parents may not be given the opportunity to articulate their own views about their parenting role, as they are faced with recommendations from professionals. Stoner and Angell (2006) interviewed 4 couples of children with ASD on their perspective of their interactions with education professionals and identified the following four common parental roles: negotiator, monitor, supporter, and advocate. Although the roles were not mutually exclusive, the authors suggested that parental level of trust could mediate the role that a parent would take. For example, if the parental level of trust of a professional was low, the parent would likely take on a negotiator and monitor role, whereas if the parental level of trust was high, parents felt empowered to adopt roles as supporters and advocates of their children. Based on these findings, the authors recommended that professionals take an active role in building trust with parents, through consistent communication, as it could lead to more positive parental empowerment and engagement.

As the picture of the research on parent-professional relationships in ASD early intervention programs is beginning to emerge, it is commonly perceived that even though professionals may frequently interact and work with diverse families, they may not have a sufficient understanding of families' experiences and beliefs about the diagnosis, nor of their perceptions of the interventions and of their role in this collaborative relationship. Differing parental views about the parent-professional relationship could make intervention partnership more difficult.

Present Study

Current research on ASD prevalence continues to demonstrate an increasing trend in the prevalence of this disorder (e.g., CDC, 2014) and at an earlier age, thus justifying the need for ongoing research in the field. The diagnostic process for families can be a challenging experience (e.g., Keenan et al., 2010) and should continue to be investigated as it may shape future experiences with services and professionals. More specifically, as research suggests, children of diverse ethnic backgrounds tend to be diagnosed at a later age (e.g., Mandell et al., 2009), consequently delaying access to ASD treatment services. Following a diagnosis, immigrant families may experience a wide range of beliefs and perceptions regarding its cause and course (e.g., Herbert & Koulouglioti, 2010) and thus be more inclined to follow particular interventions (Dale et al., 2006). Finally, even when families are receiving services, issues in forming a collaborative partnership with professionals may arise (e.g., Stoner & Angell, 2006) and this may be challenging for immigrant families who are navigating new institutional systems (Yu et al., 2008). Although some research has demonstrated that parents may experience difficulties in their relationship with professionals, more information is required to understand how parents experience this and how parents make meaning of these experiences as they seek ways to help their children. Furthermore, parents' future expectations for treatment and how they may re-negotiate their role(s) as they understand their children's development may provide insight into the experiences of these families. In addition, gaining a better understanding of how parents view their relationship with professionals, their perceptions of the interventions, and their future expectations for their child may provide insight for professionals who are interested in understanding parents and developing collaborative and culturally-responsive partnerships with parents. Lastly, exploring parents' view of the diagnosis, services, and relationships with professionals using an eco-cultural framework will reveal the contextual issues surrounding their beliefs and perceptions in order to develop better intervention.

As Montreal is a highly multicultural metropolitan, it is important to ensure that professionals understand the diverse needs and specific beliefs of families regarding their child with ASD. Therefore, the aim of this study was to utilize a phenomenological approach to learn about the unique experiences that immigrant families live through when obtaining an ASD diagnosis and how they describe and make meaning of the process of obtaining access to and use services, their relationships with professionals, their role(s) as parents, and their future expectations for their children's development. The following research questions guided this inquiry:

> How do parents describe and make meaning of the diagnostic process and how do they experience selecting, accessing, and using services?
>
> a. How do parents experience, perceive, and understand their child's diagnosis and the diagnostic process?
> b. How do parents experience and perceive their child's treatment services?
> c. How do parents describe their experiences with professionals? What is the nature of the parent-professional relationships within the context of the treatment program?
> d. How do parents understand their role and what are parents' future expectations for the course of their child's development?

Methods

Research Design

Due to the broad and exploratory nature of this study's focus, a qualitative approach was utilized to learn about parent perceptions of, and experiences with, their child's ASD services.

More specifically, a phenomenological approach was utilized to gain an in-depth understanding of parents' lived experiences with obtaining an ASD diagnosis for their children, selecting, accessing, and participating in intervention services, and in their relationship with professionals. Phenomenological research is a form of qualitative research that focuses on understanding and interpreting the conscious experiences that people have of a particular phenomenon of interest (Merriam, 2009). The paucity of research on this topic confirms the importance of using a phenomenological approach as a preliminary method of gaining a basic understanding of parent perceptions of their child's ASD diagnosis and intervention services.

One characteristic of phenomenological research is the focus on the subjective experiences that individual's have, in relation to a phenomenon, and therefore human subjects act as the primary method of data collection (Englander, 2012). Consequently, in-depth interviews were conducted with the participants in the present study in order to understand the meaning of their experiences with obtaining a diagnosis for their child, seeking and participating in intervention services, and in their relationship with professionals. The interviews were one-on-one and semi-structured to guide the participants to reflect on the topic of interest, but were also flexible and open-ended to allow the participants room to explore the entire scope of their beliefs and views (Merriam, 2009).

Recruitment

Seven participants were recruited from a local government-funded autism treatment center and one participant was recruited from a private autism treatment center. The primary investigator approached the directors of these centers to discuss the purpose and procedures of the study and encouraged them to share that information with parents. Directors were provided with letters specifying the details of the study (see Appendix A for information letter to directors), and consent to contact forms (see Appendix B for consent to contact forms). Any interested parents were given the information letters (see Appendix C for parent information letter) and consent to contact forms, thus giving consent to phone them to discuss their interest in participating. The primary investigator then directly contacted parents to discuss the details of the study and arranged a time and setting for the interview.

Participants

A purposeful sample of eight families of children with ASD, between the ages of 2 and 6, were recruited to participate in this study. Purposive sampling (or purposeful sampling) is a procedure that is typically used in qualitative research, whereby participants are selected by meeting particular criteria that establishes them as valuable for learning about and understanding the research topic (Creswell, 2012). The selection criteria used in this study were parents who had a child with a diagnosis of ASD that was (a) attending an autism intervention program, (b) 6-years-old or younger, and (c) had at least one parent that had been residing in Canada for 10-years or less. These criteria were established in order to ensure that all of the participants could contribute rich and meaningful information to the central phenomenon of this study (Englander, 2012).

Table 1 provides relevant demographic information on each of the families that participated. Participating families came from varied backgrounds and had been living in Montreal for an average of 7 years. Mothers participated in all interviews, except for one, in which both the mother and father participated in the interview. A brief overview of each of the families' background follows.

Rivera family. The Rivera family came from Mexico. The father had been living in Montreal for 28 years and the mother for 4-years. Their only child, a 5-year-old boy at the time of the study, was born in Mexico. At home, the family primarily spoke Spanish and occasionally

English. Their son was diagnosed with ASD at age 5, at a local Montreal hospital, and had been attending intensive public and private ASD treatment programs in Montreal.

Santos family. The Santos family was from the Philippines. The mother had been living in Montreal for 11 years and the father for 7 years. Their son, 5-years-old at the time of the study, was born in Montreal and later diagnosed with ASD by a private Montreal psychiatrist at the age of 3. At home, the family speaks Tagalog, English, and a little bit of French. At the time, he was enrolled in a government-funded consultative treatment service in Montreal.

Hendrickson family. The Hendrickson family emigrated from St-Vincent and the Grenadines and was a single parent home. The mother had been living in Montreal for 10 years and took care of her two children: son, aged 6 years and daughter, aged 3 years. They spoke exclusively English at home. The son had just been recently diagnosed with ASD just prior to turning 6 years old, at a local hospital, and was enrolled in consultative government-funded treatment services in Montreal at the time of the study.

Lin family. The Lin family was a single parent home. The mother emigrated from China 10 years ago. Her only son, 6 years old at the time of the study, was born in China. At home, they mostly spoke Mandarin. He was diagnosed with ASD at the age of 2 years and 8 months at a local hospital. He had received intensive government-funded intensive services.

Vivas family. This family came from the Philippines. The father had been living in Montreal for 9 years and the mother for 5 years. At the time of the study, they had a 5-year-old son that was born in Montreal and an 8-year-old son. At home they spoke Tagalog and English. Their younger son was diagnosed with ASD at a local hospital in Montreal at the age of 4 years and 8 months and he was enrolled in a consultative government-funded treatment program at the time of the study.

Kalou family. This family was a single parent home. The mother was born in the Ivory Coast and had been living in Montreal for 8 years. She had two sons, a 6-year-old boy and a 4-year-boy. At home, they spoke French. The oldest boy was diagnosed with ASD, at the local hospital in Montreal at the age of 2.5 years. Her second son was diagnosed with ASD at the local hospital at 3 years old. They both attended intensive government-funded treatment programs.

Aknin family. The Aknin family was from Algeria and both parents had been living in Montreal for 5 years. The parents had two children: a girl, aged 7 years and another girl 5 years of age, at the time of the study. At home, they spoke Berber and occasionally French. The younger of their two children was diagnosed with ASD, at a local hospital in Montreal, at 3 years old. She was then attending a consultative government-funded service.

Tanzir family. The last family was from Algeria and the parents had been living in Montreal for 8 years. At the time of the study, they had a 6-year-old boy, 4-year-old girl, and a 3-year-old girl. They spoke Arabic, French, and a little English at home. When their son was 2 years old, he was diagnosed with ASD, at the local hospital in Montreal. He then attended an intensive government-funded intervention program.

Table 1

Participant Demographic Information

Family	Home Country	Years in Montreal
Rivera	Mexico	4
Santos	Philippines	7
Hendrickson	St-Vincent and the Grenadines	10
Lin	China	10
Vivas	Philippines	5
Kalou	Ivory Coast	8
Aknin	Algeria	5
Tanzir	Algeria	8

Procedure

Following the phone call to determine interest and schedule an interview, the primary investigator met with the families, at their convenience, to again review details of this study and obtain written informed consent (see Appendix D for parent consent form). Just prior to commencing the interviews, participants were asked to complete the demographics form (see Appendix E for demographics form).

The interviews took place in quiet locations that the participants had selected, such as their home, coffee shop, community center, and intervention program center. An interview protocol was used for the first interview as a guide (see Appendix F for interview protocol); however, all parents were given the chance to discuss any topics. The interviews were audio-recorded and lasted between 45-120 minutes and were conducted in English or French, as per the family's preference. Following transcription and preliminary analysis of the interviews, all parents were then contacted for a short follow-up interview. All families, with the exception of one, were met in person by the principal investigator for an interview of 30-45 minutes. One family was unable to participate in the follow-up interview due to illness.

Data Analysis

The data for this study consisted of transcribed interviews and completed demographics forms. The transcriptions were hand-coded and analyzed using the Microsoft word, track changes program. Emergent coding analyses were carried-out while data collection was ongoing, so that follow-up interviews could be conducted to obtain further information or clarification.

Data were initially analyzed inductively and then deductively and were comparative in nature (Merriam, 2009), meaning that the themes that emerged from the data were constantly compared within and across participants and questions. To organize the analysis, the participants' words were used to describe the various themes that emerged and eventually the codes were grouped together to construct broader categories, referred to as axial coding (Merriam, 2009). See Appendix G for data analysis coding scheme. The analyses provided an opportunity for rich description of the participants' experiences, as well as provided insightful interpretation that was grounded in the participants' accounts. The focus was on the meaning the participants made of their experiences with ASD diagnosis and services and all interpretations were centered on this question.

Data Authenticity

Various methods were employed to ensure that the data from this study were credible and authentic. Member checking was conducted by asking parents to provide their email or mailing address in order for the principal investigator to send a final summary of the data obtained during their interviews. Participants were then asked to read the summary and determine if it was an accurate representation of their views expressed during the interview. Any inaccuracies were corrected as per the parents' requests. Similarly, participants' quotes, verbatim, ensured credibility and confidence in the data presented (Merriam, 2009). Finally, cooperative inquiry (Brantlinger, Jiminez, Klingner, Pugach, & Richardson, 2005) with the research team (i.e., graduate student and supervisor) was conducted. Regular meetings were held to ensure that the coding was reached by consensus, any biases were discussed and multiple perspectives were sought to ensure different perspectives and interpretations were considered.

Findings

A qualitative analysis of 15 transcripts from the in-depth interviews conducted with families of children with autism uncovered numerous themes related to their unique experiences in obtaining an ASD diagnosis and services for their children. The themes that emerged from the data will be discussed in relation to this study's guiding research questions. Specifically, the following four research questions were considered:

a. How do parents experience, perceive, and understand their child’s diagnosis and the diagnostic process?

b. How do parents experience and perceive their child’s treatment services?

c. How do parents describe their experiences with professionals? What is the nature of the parent-professional relationships within the context of the treatment program?

d. How do parents understand their role and what are parents’ future expectations for the course of their child’s development?

In addition, this study utilized an eco-cultural framework to derive an understanding of the families’ unique situations and circumstances as it relates this study’s phenomenon of interest. This cultural and contextual framework, derived from the families’ discourse about their backgrounds and current home contexts, was analyzed to help capture their interpretations and understanding of their unique beliefs, perceptions, and experiences in obtaining a diagnosis and services for their children. Prior to discussing the findings as they relate to this study’s research questions, a brief summary of each participant’s contextual and cultural backgrounds will be presented.

Participant Backgrounds and Current Context

Mrs. Rivera. Mrs. Rivera grew up in Mexico City with her parents and siblings. When recounting her upbringing she focused on her positive experiences at school. She recalled that school lasted the entire day, from 7 a.m. until 7 p.m. and involved a more “global education, artistic and the … traditional dance in Mexico, doing research, doing things”. When growing up in Mexico her mother and most mothers at the time remained home to take care of their children. Mrs. Rivera finds that now in Canada most women are more independent and leave the home to work. While she respects this decision, she is conflicted with her beliefs about the importance of children needing their mothers. She fears that leaving children at such an early age can be detrimental to their social and emotional development and reported to have observed these effects: “I am seeing more untouching, more untouch childs, like unsecure childs”. At the time of the study, she stayed at home mom, but would eventually like to try working once her son attended primary school. She has a very limited support network, as she does not have any family in Montreal, but had made friends with some other families that emigrated from Mexico.

Mr. and Mrs. Santos. Mr. and Mrs. Santos were both born and raised in the Philippines. When asked about their childhood, they both focused on how much freedom they had. They were free to go and play anywhere, not matter how young they were, as long as they were home for dinner. When discussing how they played, both parents emphasized how they did not have technology, as children did today, and thus were forced to use their imaginations. When asked about parenting practices, they reported that their parents did not have time to be around too much; they did not give their children lectures, or directly teach them. Their role was focused on making sure the children had something to eat, sending them to school, and the rest was up to the children. They remarked that this freedom was beneficial to them: “We learn lessons from what were experiencing”. Overall, they reported that parents trusted their children more than they do here in Canada. Currently, they only have one child, they try to trust and let him develop as much as possible, but since his diagnosis they have been helping him more. They do not have any family in Montreal.

Mrs. Hendrickson. Mrs. Hendrickson was born in St-Vincent and the Grenadines and was raised by her grandparents. Her mother left them with her grandparents when she was 3-years-old and her father was never in the picture. Mrs. Hendrickson’s household was busy, with grandparents, aunts, uncles, and cousins. She reflected on her childhood as positive, with lots of love, support, and friendship from her siblings and cousins. She lived in a small village where everyone knew each other. She remarked on how different the parenting practices were as compared to here in Montreal and found herself conflicted about which approach was best. For example, she described parenting practices in St-Vincent to be more strict and contain more punitive measures, such as spanking and grounding. While she did not support spanking as a form of punishment, she did find that parents in Montreal were too permissive.

> They parent their child in the way they feel. They try to be like, ok be their friend where they feel like they would never have their child say you're a bad parent or I hate you. If you tell me you hate me it's because I think I'm doing my job cause you're not gonna get away with everything or get anything they want.

At the time of the study, in Montreal, she was a single mother and only had two cousins living nearby. She found it very difficult to manage everything without help.

Mrs. Lin. Mrs. Lin grew up in China with her parents and her brother and two sisters. When talking about her childhood, Mrs. Lin focused on the importance of school achievements and establishing a successful career in order to be able to support her parents later on. She described that her parents gave them a lot of freedom, but still focused on encouraging them to study hard and achieve in school: "Pay attention to study. Study, study". She described there to be a lot of competition between siblings and then explained that she saw herself as the black sheep of the family as she did not have a successful career like her siblings. She said that she graduated with a degree in engineering, but decided instead to pursue her passion:

> I wanted to learn philosophy, so I find a way to learn it in a Chinese traditional country and follow the master. I live in the mountain, and I quit from my job and leave all my family, and I try to have some wisdom.

She reported to be a single mother in Montreal and did not have any family here. She had made a few friends at work and in her apartment building, but rarely asked them for support.

Mrs. Vivas. Mrs. Vivas was born in the Philippines and lived with her parents and six siblings. Her father was rarely home, as he worked in the Middle East. She described her parents as very traditional, focusing on encouraging their children to go to school and not allowing her or her sisters to be alone with boys. When asked about how their traditional parenting practices and customs compared to Montreal, she focused on how technology had made everything different, from computers, cell phones, to having running water in the home. In Montreal, she lived with her husband and two sons. Only her sister lived in Montreal and she helped out sometimes, but in general Mrs. Vivas found her daily routine, of working, cooking, cleaning, and transporting children very difficult to manage.

Mrs. Kalou. Mrs. Kalou was born and grew up in the Ivory Coast. When asked about her upbringing she focused on the importance of family and how everyone lived in close proximity. She also mentioned how everyone knew and supported each other in the village. For example, she recounted that: "When a woman is pregnant she does nothing, she sits like a queen, we feed her, and we take care of the other children" *[Translated]*. Mrs. Kalou was married in her village and then came to Montreal with her husband. She was the first and only member of her family to leave their hometown. She had separated from her husband, cared for the children on her own, and did not have any family support in Montreal.

Mrs. Aknin. Mrs. Aknin was born and raised in Algeria and lived with her parents and siblings. When asked about her childhood she emphasized the sense of community, something found was missing from her life in Montreal. She recounted that her parents gave her a lot of freedom to play with friends and neighbors, as everyone knew each other in the village. She described her parents as assuming traditional roles; father worked outside of the home to provide for family and mother stayed home to cook, clean, and look after the children. She found that parents in Montreal were too permissive: "At the age of 14 everything is permitted" *[Translated]*.

She said that her parents taught her a lot about how to take care of her own family: “So, for me, the education that I got from my parents, I almost apply the exact same thing with my children now” *[Translated]*. She only had a brother living in Montreal temporarily, thus, found it difficult to manage her hectic routine without help.

Mrs. Tanzir. Mrs. Tanzir was born and raised in Algeria by her parents. When asked about her upbringing she focused on her school achievements. She mentioned that the role her parents took on was to be present: “Being present was not of a material nature, presence meant being there in person, that’s what it was like” *[Translated]*. She recalled that her parents taught her a lot about being disciplined, but also about enjoying life. Her father taught her to always see the positive side of things, which she described had really helped her get through some of the challenges involved in raising her son. At the time of the study, she lived with her husband and three children. She only had a brother and sister in law in Montreal.

Diagnostic Process

Identification of the problem. Each parent recounted their unique experience with the discovery of their child’s difficulties or atypical development that eventually led to undertaking formal steps leading up to the final diagnosis. The following four themes were related to identification of the child’s diagnosis: (a) context of concern, (b) the child’s difficulties or atypical behaviors, (c) denial, disagreement, and doubt related to concerns, and (d) parents’ preferred outcome of upcoming events related to diagnosis.

Context of concern. Immigrant parents discussed four different contexts to the initial identification of their child’s difficulties. Most of the parents were the first to identify the various difficulties or issues that their children were having before other professionals or relatives. The context to their concerns in these cases were either through comparing their child to their sibling at home or in observing their child at daycare with other same age peers. For example: “I noticed that there was something different about him when he was 2 years old … doesn't seem like he is developing as fast as a 2 year old would" (Mrs. Hendrickson). Similarly, Mrs. Aknin said: "I spoke to him [husband] about my concerns, because I was always comparing her with her sister … she did not progress like her sister" *[Translated]*. One parent learned of their son's potential difficulty during an appointment with their child's pediatrician. The mother reported that when her child was 3.5 years old "The doctor told me maybe you should look for speech therapy … because he's delayed in, you know, talking and communicating" (Mrs. Vivas). In one case, a daycare worker advised the parent that there was something wrong, "When he go to the kindergarten [daycare], the teacher tell me he cannot follow the group very well" (Mrs. Lin). One parent was alerted of some concerns about her son's development by a social worker conducting a home visit upon the birth of her second child, "I received a visit from a social worker of the CLSC at home … she asked if we wanted her to refer us to a center … because at his age he should be saying several words" (Mrs. Kalou) *[Translated]*. It appeared that most parents were the first to notice and then consulted with professionals, such as daycare workers, social workers, and doctors.

Child's difficulties or atypical behaviors. Many of the parents reported that their child had exhibited atypical developmental consistent with the ASD diagnostic criteria, such as lack of communication and social-emotional functioning, and showed stereotyped patterns of behavior (American Psychiatric Association [APA], 2013). One parent reported, "We are sure of that, that he has delays because he can't, at the age of 2, 2.5 he can say a word but not a full sentence and he's not always looking at us directly" (Mrs. Santos).

These parents mentioned noticing sensorial abnormalities, typical to ASD populations, such as sensitivity to noise. One parent described: "Always having problems whenever we go somewhere where it’s too loud he has sensitivity to that” (Mrs. Santos). Similarly, Mrs. Hendrickson said:

> I would ask the teachers how he’s doing, and they would say that if they don’t ask him to move he would stay there all day and he would not interact with other kids and he would hide his ears to noise.

While parents typically described characteristics common to the ASD diagnostic criteria, some parents described challenging behaviors that resulted from these deficits: “He couldn’t talk, he started having behavior problems with the kids, instead of ask ‘can I play with you?’ he start pushing, he start pinch them … I mean they [daycare staff] couldn’t manage him, the situation” (Mrs. Rivera). Therefore, these immigrant parents were often aware of their children’s difficulties and particularly the challenges that were preventing their children from fitting in socially with other children.

Denial, disagreement, and doubt related to concerns. Following the description of the different behaviors or difficulties that parents noted, some immigrant parents described some difficulty accepting and understanding their significance, particularly when they were experiencing other challenges such as a second child with autism, family problems, or if they felt blamed about the children’s difficulties. In some cases, parents were themselves in denial of the significance to the behaviors. Mrs. Kalou, recounted her reaction to the challenges and difficulties that arose when professionals signaled that her second son may have autism, following the recent ASD diagnosis of her first child:

> For *[Child’s name]*, I was negligent. I really did not want to throw myself into it, and well, when they told me that his older brother was autistic and then again they are going to tell me that the little brother is also autistic. So, I didn’t want to get involved again into this

> procedure because I was just getting too tiresome for my body, I was tired morally, … so, I did not want to get into this process again with *[Child's name]*. *[Translated]*

Not only was she emotionally and physically drained from having just experienced the diagnosis of her first child, this situation was made even more complex due to the lack of familial support. Given that her entire family was in the Ivory Coast, she would call them for advice and they would assure her that it was nothing to worry about. Specifically, her parents would tell her: "let it go, he will start to talk, its nothing, you do not need to stress for nothing" *[Translated]* even though they had never met the child. These mixed messages, from family members and professionals were also likely a reason for the delay in commencing the diagnostic process.

In other cases, there was similar disagreement between the parent or family members and other professionals. Mrs. Hendrickson described that her pediatrician was not receptive to her concerns:

> I noticed there was something different with him about when he was 2 years old. But his pediatrician was really not understanding my feelings, because I tried to speak to him and tell him that for 2 years old the things that he's doing it doesn't seem like he's developing as fast as a 2 year old would. But he kept blaming us so I stopped seeing him.

Mrs. Hendrickson explained that she felt the pediatrician was not taking her concerns seriously and was implying that she was a "mother who's overly protective and … a little bit paranoid". In the end, she disregarded his advice to wait it out and proceeded to seek help from other professionals. She had the courage to do this by telling herself that there was no way the pediatrician could have determined that everything was fine in the little time he spent with her son "He was not spending more than 10-minutes with him", therefore leaving the possibility that her concerns were valid.

Mrs. Aknin described disagreement about the significance of the identified problems with her spouse:

> Before, before even the diagnosis, when it was just me talking about these problems, he [husband] said to me 'listen, you always look for problems, you are always looking for problems. You have to stop reading, you have to stop looking, you have to stop talking to others, look at your daughter, she is progressing, she takes her time, that's just how she is'. *[Translated]*

She later reported that autism and the idea of diagnosing did not exist when she was growing up in Algeria and even to this day, much of her family and friends did not know about it. Even her husband, she said, took a while to understand, which may be why he disagreed with her on the significance of their daughter's issues.

Similarly Mrs. Hendrickson described:

> Even when my ex-husband was really giving me a hard time on it I said there's something wrong, and he just made me feel like oh he's just a child he will talk when he's ready, he will do this when he's ready, and I'm like yes he would but he needs a little help along the way and I can't give him the help because I don't know how to give him that help.

Other family members also disagreed with parents' concerns and provided reassurance not to worry: "My sister always telling me 'don't bother, he's gonna talk because my son is like that, too, he's not talking. When he reach 4 he's talking like a bird. It's like a new battery on him' (Mrs. Vivas). In this case, Mrs. Vivas's sister believed that everything would work out as she herself had once experienced concerns that turned out to be unnecessary. Similar to Mrs. Aknin, Mrs. Vivas discussed how the autism diagnosis was unknown to many when growing up and even to a certain extent now, in the Philippines.

> Because honestly, in the Philippines, if there’s a disability they didn’t know that autistic child. Because it’s hard for them to go to the doctor, to go to the specialist, and to pay. Because that is a thousand, thousand, thousand, money. So for the average family they didn’t afford to go the specialist to assess if there’s something wrong with their child.

These examples suggest that the lack of understanding and knowledge about autism and the process of obtaining a diagnosis, among immigrant parents and their families, may foster disagreement and denial in reaction to their children’s issues.

Some parents also described their own feelings of doubt as to the significance of the identified problems:

> In the beginning I do not believe it, but, because he’s my first kid, and I think he is too young. … I only have one kid. I do not have another kid to compare how different they are. And for me, you know, I think everything is normal. (Mrs. Lin)

Similarly, Mrs. Hendrickson expressed:

> Like I doubted myself and believing that; ok give him time and see if he would start doing it on his own. So that’s the only thing I sometimes struggle with, like, that I didn’t just go with my gut feeling and fight for my child more, instead of waiting until he was almost four years old.

For both of these mothers, at the time of their initial concerns, they did not have any other children or family around to compare their children to, which may have contributed to doubt. When Mrs. Hendrickson finally took action to get her son help, her youngest girl was 9 months old. It was at that early age, when her daughter started to say words and imitate speech, something her son had never done, that she felt more confident about the validity of her concerns and took action in seeking professional assistance.

Parents' preferred outcome of upcoming events related to diagnosis. Following their experiences in processing and reacting to their children's identified issues and challenges in development, parents described having pre-conceived expectations about the preferred outcome of upcoming related events associated to the diagnosis. Some parents described expected outcomes that were not related to ASD, but simply to a developmental delay or as a consequence of physiological or sensory issue. For example, when a pediatrician recommended that Mrs. Vivas get her son's hearing assessed before proceeding with further testing, she immediately considered this as a possible reason for her son's communication delay: "Maybe because where you are *[Child's name]* is like delayed it's maybe he doesn't hear or something happened to her ear" (Mrs. Vivas). Other parents seemed to accept that a formal ASD diagnosis was approaching and described actually wanting to get it in order to begin services, or ensure that their child would have access to services in school: "At the end of the day we believe that that code [diagnosis] was the best thing for *[Child's name]*" (Mrs. Rivera). Mrs. Tanzir tried to remain positive, as her father had taught her and tried to focus on how getting the ASD diagnosis would open doors to services:

> Well me, I believed, I believed that there would be services and that we would get help quickly, so I was waiting for once we had that paper, that it would open many doors to help my child more rapidly. *[Translated]*

Although it was sometimes challenging for these immigrant parents to accept the diagnosis, they were more easily on board when the diagnosis was attached to services. In other words, parents were less likely to be troubled by issues with denial and disagreement as they were instead focused on obtaining services.

Formal diagnosis. The period of the formal diagnosis was for most families a long and complicated process. Immigrant parent's descriptions of their lived experiences of the actual diagnostic process were categorized into four themes: (a) context (location and professionals involved), (b) experience with process, (c) reactions to final diagnosis, and (d) coping strategies/acceptance.

Context of diagnosis. Most immigrant parents described that the formal diagnosis took place in a hospital with a multi-disciplinary team of professionals. For example: “The whole team with the speech therapist, the occupational therapist, an entire team to do the evaluation” (Mrs. Aknin) *[Translated]*. Some parents did not want to wait for the assessment and paid for a private diagnosis with a psychiatrist:

> We wanted to help him right away so we called a doctor, one of the psychiatrists on the list was *[psychiatrist’s name]* and right after then, she was the one who evaluated him, for I guess 6-months. I don’t remember how, it’s, I guess, yeah, not 6-months it’s a lot of sessions but it’s not 6-months I forgot already. (Mrs. Santos)

Several immigrant parents lived in a region of Montreal that had a small developmental clinic that could do the diagnosis: “They do not accept everyone because they do not have enough staff, it’s just like a small organization” (Mrs. Tanzir) *[Translated]*. Therefore, there were multiple ways to get a diagnosis and for some it was a matter of learning to navigate the system and finding a more expedient route, which was more costly and for others, they followed what was available in their community which often meant a longer waiting list.

Experience with process. Overall, while immigrant parents had varied experiences with the process of the diagnosis, some common themes emerged. One theme related to the process included inappropriate questions that were asked. Mrs. Rivera recounted: “One of those questions was: ‘what do you think marriage is?’ … and then another: ‘do you like weddings?’. As this may have been a general knowledge question, the parent could not see the relevance of the question for a young child. In addition, this parent also discussed how she had to do a lot of translating during the assessment as her son was misinterpreting the questions because they were asked in English, which was not his first language,

> I ask him in Spanish ‘My love, Christmas is Navidad and then what is marriage for you’ (in Spanish) and he was like ‘oh, well mommy you and daddy you are married’, Esposo’s it’s in Spanish ok, but in English he don’t know.

The next common theme involved the complexity of the process, in terms of the number of steps that had to be completed (e.g., numerous appointments and paper work), the required interactions with many different professionals, and understanding the actual information given by the professionals. Mrs. Hendrickson reported: “So there were steps the hospital had to take before he was transferred over for the final, so all together it was like four or five different people that I saw”. Most commonly, parents described interactions with psychologists, psychiatrists, pediatricians, speech and language pathologists, and occupational therapists. Some parents also described interactions with social workers, nurses, and educators during this process. These were all professionals they had not interacted with before and there were many new terms and interventions being discussed for which they had no knowledge about. Parents reported that they had a difficult time understanding what was going on:

> Yes, there’s a lot I didn’t understand. So, that’s why sometimes I’m gonna say ‘what? Could you please explain to me why? What really happened? What do you want me to do as a parent?’ Because, you know, I didn’t know what I supposed to do. (Mrs. Vivas)

Similarly, parents had difficulty understanding some of the technical terms that professionals used: “Yes those are terms that are specifically used with those kinds of diagnosis … so we have to ask that. … And then research a little bit about it also. … Just like looking up on the computer” (Mr. Santos). In addition, concepts and procedures were difficult to comprehend for some families due to language barriers:

> Yes, yes of course, it is because my English is never that good. But I go to the Internet. Thanks for the Internet! I check everything by myself and in Chinese. I try to understand everything by Chinese but sometime they are a little bit different from system here and the Chinese. (Mrs. Lin)

Some parents described that professionals were in disagreement about the actual diagnosis, requiring them to run further testing or make arrangements for a follow up testing in a year. For example:

> We will not say, we cannot say, that *[Child's name]* is autistic, has autism, and we were like 'ok, so?' no, but we believe that he needs that code, because we believe that *[Child's name]* needs help and services and because of that, we will ask you, is one of the things that we never do, to come in 18-months to reassessment. (Mrs. Rivera)

For Mrs. Tanzir, her son was too young for them to confirm the diagnosis: "It's for sure that at 19-months they cannot confirm anything, but already symptoms were observed. … They told me that they would re-do it at 24-months, but they suspect that it is autism" *[Translated]*. For Mrs. Kalou, professionals were in disagreement because he had an older brother with autism and they supposed the younger brother may have just been imitating the older brother's behaviors. Nevertheless, they decided that it was best to say that he had a diagnosis:

> So, they did the diagnosis and they found that he was autistic because, they said that they could not associate all of the elements, … later on maybe he will have other things that may develop, so the best would be to say in general that he is autistic so that we can start working with him because if they say nothing and later on discover other complications, so we said 'ok'. *[Translation]*

Finally, the most common theme, related to immigrant parents' experiences of the diagnostic process involved having to wait. All eight parents described having to wait for the diagnostic process to begin or reported that the actual process itself took a long time. Mrs. Rivera described her frustration with having to wait: “That waiting list for me, it’s like that system, that you, the government has in that system, I don’t know what’s happened, I don’t know, really I don’t know what happened, never move, nobody called me, ever, ever”. Despite the waitlists, her experiences growing up in Mexico City had taught her to persevere in spite of these obstacles: “Because I come from a very rough country and you have to fight for everything in Mexico”.

Waitlist times varied from 6-months up to 24-months. One parent described that waiting was not what they expected from the services in Canada:

> But it’s hard waiting. That’s the problem waiting, waiting, everything is waiting list. And how come? That’s what, how can I say, Canada is progressive country but still the services given the people still have to wait that’s the problem. (Mr. Santos)

Overall, the diagnostic process was long and complicated and often the process and outcomes were not clearly explained to parents. Immigrant parents described that they had to navigate resources that were new to them and they were impacted by the new technical terminology, extensive list of professionals they had to interact with, and the lack of clarity and consensus between professionals. Finally, the long waiting time was frustrating for parents who were concerned that their children were not developing normally and they could not do anything to help them.

Reactions to final diagnosis. All immigrant parents described the actual confirmation of the final diagnosis to be difficult. Themes that emerged from their experiences include sadness, confusion or disagreement about diagnosis, and guilt. Mrs. Aknin described that she was not even able to speak after being told and that it took some time to process. Only until they mentioned the word ‘handicap’ did it really occur to her that there was something wrong with her daughter:

> But, I could not say anything, sincerely, I could not say anything. After she asked me if I

> understood, three times she asked the question ‘do you understand what we are telling you both?’ ‘Yes, we understand. No, no questions, no questions’. …After, only once she said the word handicapped did it, it’s like I was holding back my tears and I didn’t want to imagine that because it was like she was confirming that she was handicapped, I was thinking about the handicap, but I couldn’t explain it. *[Translated]*

Mrs. Aknin later recounted that she had an aunt with a physical handicap (unable to walk) and recalled when they were younger: “The kids would laugh at her … . I would always protect her, ‘why are you laughing” *[Translated]*.

Even when parents expected and felt prepared to hear the confirmation that the diagnosis was autism, it was difficult:

> The fact it was confirmed was still like a pinch. It’s completely normal, it’s a moment of sadness, it’s then that I, I don’t really remember shedding a lot of tears about the state of my child because he did not need my tears, but it was at this moment that I shed tears because it was so intense when they said ‘yes that is what it is’. (Mrs. Tanzir) *[Translated]*

Some parents described feeling confused about what to do next, or even what the future held for their child. Mrs. Vivas described:

> I’m just keep thinking, when I’m getting older what happens to [child’s name]? Even though he’s having like big brother, I always think when you’re bigger you have your own life. … Because your mommy and daddy is getting older, you [big brother] are the one who take care of [child’s name].

Mrs. Santos described similar uncertainty: “Really upset for a week we, I was crying, thinking what’s going to happen to him in the future, who will help him if he’s always like that, no improvement at all, that’s what’s in my mind before”.

The final theme that emerged from the data included parents describing feelings of guilt following the confirmation of the diagnosis. Mrs. Hendrickson described feeling guilty that she had not begun the process sooner:

> The only thing that I ever said I had a little bit of regret, it was not doing it sooner. … I still feel a little bit of guilt. I could have done anything… like could it be different if I had done anything sooner?

For Mrs. Kalou, guilt was expressed following the diagnosis because she felt that she would have received better services had she not moved into a new territory: “It’s just that I regret, because he *[Child]* does not have the services that *[First son’s name]* had when we were in *[Name of municipality]*, it was not the same service that we get here” *[Translated]*.

Coping strategies/acceptance. Each parent described their unique experiences with the journey of accepting their child’s diagnosis. Some themes that emerged include: (a) use of religion as providing comfort and peace, (b) comparison to more severe cases, and (c) the belief that recovery was possible, thus always remaining hopeful and feeling positive about the future.

Mrs. Vivas described herself as Catholic on the demographics form and she came to accept her son’s diagnosis by finding solace in her spiritual beliefs: “So maybe it’s easy for me to accept because maybe god gave it to us”. Likewise, Mrs. Kalou, whom also identified herself as a Catholic said: “It’s really difficult to have autistic children, but that’s life, I don’t know if god chose to give autistic children to strong people or not, but for me, it has made me a very strong person” [*Translated]*. Mrs. Aknin also made reference to her spiritual and religious beliefs as a Muslim: “In any event, we believe in God, so if he has decided, then it is God who wanted it like that and we do not have a choice” *[Translated]*.

Several immigrant parents described the process of comparing their child to others that were more severe. Mrs. Kalou commented:

> Well, what they, because we had other information, we saw other children too that had the same difficulties, so we went out a lot to the park and we saw other children that had symptoms, who reacted in a certain way and we tried to compare to *[Child's name]* and we said that he has the same problem, but the others are even more severe compared to him, so it motivated me, I told myself why can't I give myself the courage to help our child progress, so that's how I got the motivation, and I really got involved in his therapy, and so it was a little like that. *[Translated]*

Parents also described reaching acceptance once they learned that the diagnosis could be overcome or significant improvement could occur. Mrs. Hendrickson described:

> It was still hard to hear, that you have a child who has a disability. But it was good that what I heard that in time he can grow out of it. …With continual help that he's having now, 6-7 years he could be at the normal range of another child at his.

It seemed that immigrant parents' reactions to the diagnosis were closely related to finding hope by focusing on spiritual beliefs, less severity in their child's symptoms and by focusing on the future.

Beliefs about ASD. Parents expressed three main themes related to their perceptions of what autism actually is. In several cases, parents expressed that their beliefs about autism were continuously evolving from before having children, to the initial diagnosis of their child, and then following a year or two afterwards. Many parents described learning about ASD through the Internet, books, from other parents, friends, and from professionals.

The initial perception, that some immigrant parents described, of what autism was involved the notion that it was a lifelong illness, suggesting suffering and hopelessness for the parent and the child. Mrs. Hendrickson described:

> It's scary. … If I didn't see everything now I would think it meant a life of suffering. A life where you're going to always have challenges, it's like you're going to always be stuck – like is this the end of my life? Does that mean I'm gonna have to stay focused on my son? Like I have nothing that I can do for myself? It's like that's how I felt at first when I heard that I'm like wow. I thought of going back to school and getting a career for myself, but now is this the end of me?

Other parents believed that it was a temporary condition. Mrs. Vivas recounted:

> Because my sister, they know that *[Child's name]* is autistic, but they kept their finger cross that *[Child's name]* is going to be, like when he grow up, he's going to be like a normal boy. Because there's a lot of autistic people that when they grow up they gonna like have a normal one. So they believe that someday *[Child's name]* is going to be like a big boy. Sometimes, you know, I don't know either.

Mrs. Vivas later explained that what she heard about people's personal experiences with their children or family members improving, with the help of medication, as they got older: "And my nephew, he has a friend, and her friend brother is autistic. But he's like taking a medicine, I don't know, but now he is good and he is in college in Concordia, and he's good".

Mrs. Hendrickson had changed her beliefs about what ASD was: "With time he would grow out of it. With continual help that he's having now, 6-7 years he could be at the normal range of another child at his… by then with the continual help and so forth". Similarly Mrs. Tanzir:

> It's like, my child gave me an image of a normal child, it's not that he was born with it, he had started to talk, I saw him, so I hold on to this, that he will return to this image of a normal child because I had seen my normal child, it's not like I had not seen him. So, it's this that gives me courage. *[Translated]*

Some immigrant families discussed autism to simply be children with specific deficits and delays. For Mrs. Rivera, she describes these deficits to be common to most people, even herself:

> We believe that even us, I don’t know if, believe me maybe I have, I am autistic, I mean I have problems learning how to write properly. Instead of write an S, I write an R, maybe it’s a, I mean its not a dyslexia, or dislalia, I have no idea, but that condition exists and its not particularly for poor people, for rich people, for people that they couldn’t to the school, the people that don’t have nothing to eat, I mean its for everybody.

Some immigrant parents reported that there continued to be feelings of stigma and prejudice related to the diagnosis. Mr. and Mrs. Santos stated:

> F: Yes but by simply listening and simply analyzing that word its really hurting one’s feelings already and that’s what we felt when we heard that.
>
> M: As if your child is having a mental disorder.
>
> F: Yeah, that’s the hard take, but like what I said that’s the first thing we felt that’s what that word means to us.

Mrs. Hendrickson discussed how happy she was that her son would grow out of his disorder as she felt that having a label of autism was stigmatizing and would be limiting for his future: “So that was good to hear that even if he have it he will not always be stuck under that bracket of autism spectrum disorder. Once he had the help he would grow out of it”. When asked what others believed about autism, Mrs. Hendrickson said:

> Because people expect autism … when you say ‘autism’ they’re supposed to look with the bulgy eyes or limp face – they’re expecting that look. So when I say he has autism they look at me like ‘oh they just give you a diagnosis to make you feel happy’. So that hurts sometimes, when you hear those kind of things.

Similarly, when Mrs. Lin was asked what others believed about autism, she said:

> Normally I think, you know, the people they just say, “oh you’re not lucky, take care”. But they do not spend a lot of really time to think what’s happening if this is far from them. Yeah, perhaps they think you are not lucky. But it’s ok.

Therefore, it seems that immigrant parents were concerned about the stigma associated with their children’s disorder. Some believed that their children would eventually outgrow their difficulties or make significant improvement and as such, had hope for the future. They believed that others would accept their children if they made significant improvement and therefore, getting the right help for their children was important.

Causes of ASD. Some parents discussed biological causes of autism,

> Me, I always asked is it wrong with me or my husband or because my first kid is normal kid. He’s, like, if *[child’s name]* is delayed he is very smart. So, it’s like…it’s not… that’s why I keep talking to myself “it’s from me or my blood is not good or my husband blood is not good”. So it’s like asking myself like that. So it’s hard. (Mrs. Vivas)

Mr. Santos expressed that he was told that genes caused autism, but he and his wife did not believe that it was the case for them, as they did not have any family history of autism:

> Probably if I were the one to answer that question were asked before so I could say yes cause that could only be taken probably by genes which in our history and family both we don’t have any single one gene for that. That’s why it’s so hard to explain. Why are these things happening, why are these kind of findings are there.

Similarly, Mrs. Hendrickson shared:

> Every child is different; some are born that way so the cause was not my fault. It was just genetic, it just happens. It doesn’t have to be in the genes of the parents – none of the parents have to have anything that cause or give their kids; it’s just the genetics of the child that they develop.

The next theme that emerged from the data was biomedical causes to ASD. For example, Mrs. Tanzir described:

> Now the factors that are common to the world, in the world, are two things, according to me, it's the poor diet and vaccines. It's everyone in the world that is vaccinated and it is everyone in the world that does not eat well. I mean, they eat a lot, but they eat industrial things, but what causes, I believe it's the vaccines that cause. *[Translated]*

Later in the interview, when describing her upbringing in Algeria, Mrs. Tanzir described her admiration for her mother's love and care in preparing good healthy food and taking care of the children, which was clearly in contrast to the over-consumption of industrial foods today.

> My mother, she was the mother that stopped her job because of us [children], she had decided to stop in order to stay at home to raise us, so she was a mom that would wake up early every morning, think about what to make and then make healthy food for her children.

Some parents felt that their child's ASD was caused by complications that arose during pregnancy, such as maternal stress and poor diet. Before learning of genetic causes, Mrs. Hendrickson initially thought: "I thought it was my fault – like I did something wrong, like I didn't eat properly when I was pregnant". For Mrs. Kalou she did not learn of any definitive cause, but heard that stress could be a factor and therefore believed:

> Well, for the moment people say that they have not yet found a cause, they can't find the cause, but people are making links to stress that the woman undergoes during pregnancy, but I, in any case, I can say maybe it is that, because I felt a lot of stress during both of my pregnancy's. I felt more stress with *[First child]* than with *[Second child]*, so I lived a lot of stress and I wonder maybe that had some influence on my pregnancy and so it affected them psychologically. *[Translated]*

Returning to Mrs. Kalou's stories about her customs back home, where she described that pregnant women were constantly surrounded by family support and are made to relax while other take care of them, it is understandable why she would have felt stress during pregnancy. While pregnant in Montreal she had no family support and was adjusting to a foreign country with new and challenging obstacles: " It was so different [from home] and it's hard here because there are seasons, there is winter, so all of this made it psychologically and physically very difficult" *[Translated]*.

Mrs. Lin described that her pregnancy was unplanned and she was initially sad about being pregnant and she attributed the cause of her son's ASD to these unpleasant feelings she had during pregnancy:

> Yes. I do believe that it's because of me. Because, even now, I think everything come from me. Because when I pregnant I feel not happy. I'm really not happy when was pregnant. I did not want him for a long time. Even now I still think it is a reason. … Even now sometimes during morning when he wake up he cries, and there's no reason for why he cries. But because when I pregnant I always cry.

Following her divorce in China, Mrs. Lin moved to Canada: "After [divorce] I feel a little, not a little, a lot of sad. I tried to find a new place to start my new life, so I come here". When she became pregnant, out of wedlock, in Canada with her son, her family was not pleased: "Before he's born they gave me a lot of pressure to not let him and to not get him". She decided to have her child despite their disapproval and raised him on her own, without any support from her parents or her son's father. When asked if she told any professionals about her beliefs on the cause of her son's autism, she replied:

> Yeah, I speak a lot, because they [social workers] say it's not a reason, don't believe that. It's a gene or something like that. But you know, I come from a country where it's traditional culture. When I was young I learned something like that. I still do believe, it is

> for some reason; it comes from me because I was really not happy.

Therefore, she concluded that she was responsible for her child’s difficulties, as she did not have a positive pregnancy and had lacked an adequate support system during her pregnancy and after the delivery.

Finally, some parents discussed causes related to nurturing after the child was born. For example Mrs. Aknin attributed her daughter’s ASD to starting when she put her daughter in daycare and therefore was lacking an attachment: “Right up until 7-months, for me it was at that age that I put her into a daycare, I returned to my studies and it was then that I noticed, like a detachment from me” *[Translated]*. Even when professionals told her that this could not be the cause she said:

> Yes, I had spoken to the same paediatrician that had given the diagnosis, I said ‘maybe it is because of a lack of affection?’ She said ‘listen, the problem was before, before, because maybe it is genetic, maybe we don’t know the exact origin, but its not’. … But I can’t, maybe, up until now maybe it is because of that. If I was, maybe with her she wouldn’t, she wouldn’t have the same problem. *[Translated]*

When exploring the information that she provided about her upbringing in Algeria; significant emphasis on family, the community, and mother as primary caretaker for the children; it is understandable why Mrs. Aknin mentioned attachment and mother’s presence as perceived causal factors in her daughter’s ASD.

In these examples, some parents did not accept when professionals presented the cause of their children’s autism to be related to genetic issues. Some reasons to refute this possibility included not identifying anyone in their family with similar problems, believing that it was linked to difficult conditions during their pregnancy due to their immigration status that led to inadequate family support, or that it was a due to specific behaviours exhibited by the parents, such as depression or lack of a positive environment like they would have had had they been back home in their home country.

Beliefs about treatment. Parents' report of their beliefs about the treatments of ASD varied, but tended to correspond with their beliefs about the cause of ASD. For example, Mrs. Aknin believed that the cause was related to attachment issues and thus spoke about treatment as her child requiring her attention; this was consistent with her own upbringing of what was expected of a good mother, to be there for her child especially through these difficult times. She commented on her decision about whether or not to return to school as she had once intended before her daughter's diagnosis:

> After I said no, I will not return to school, because it was before, before the beginning of the session, when I was at home, I kept her with me, because I noticed she was changing because she had spent two months with me. We had noticed a change, so it was me who had the problem, it was me, so I needed to stay with her. *[Translated]*

Educational and behavioral programs were also viewed as important treatments discussed by parents:

> It's just only what they tell us that its a program you have to go with this we have to go with that we have to give like this. Whatever they tell us we follow it and we know it helps. (Mrs. Santos)

Similarly Mrs. Vivas, currently working as a nurse in Montreal said:

> Because it's not like we go to the doctor and ask for like a Tylenol and after that he cured. It's not like that. This is not easy like that. We don't have any treatment, but they're going to be trained. It's gonna be trainable so that is the, you know, the big advantage. They're not cured but they are trainable.

While Mrs. Hendrickson believed that the treatment was primarily focused on behavioral and educational programs, she did mention that medication was a component:

> So the treatment is not always medication. Because at first when I got my diagnosis a friend of mine said, ‘oh why do you let them do that? They’re going to just pump medication into your child’. And it’s been a while, and up to this day I’ve never had one medication prescribed for him. All I got was help from people who are helping him work. So when people hear about autism they get scared and think it’s medication, but there’s no medication.

Mrs. Tanzir described her disappointment with the use of medication for children with autism:

> The problem is the percentage of parents that let them go to medication, it’s too many. This causes me pain, because I am a mother and I imagine the child is already not well and then there is no such calming medication, even if the doctor says ‘no, it will help, they will help’, there is no medication, never any that will not give secondary effects. So, you’ll just be giving that to a young child and then continuing to give it for the rest of their life. *[Translated]*

Here, parents had different ideas about to the optimal treatment for their children. Many were concerned about the long-term effects of medication as well as the fear that professionals would push parents into giving medication to their children. This was consistent with their own beliefs about child rearing and mothering, believing that they as mothers would need to provide the conditions to help their child improve despite recommendations from professionals.

Treatment Services

Type and context of service. Immigrant parents experienced a multitude of different services prior to, during, and after the diagnosis. Table 2 provides a list of the principal public services that the families received following the diagnosis. Half of the families received IBI services for an average duration of 13.5-months. The remaining families received weekly consultative services with an educator. Some families had experiences other programs, such as child stimulation groups, parent support groups, speech, or occupational therapy. These services, however, were described as both less intensive and shorter in duration. All government programs that parents described attending primarily took place in a center. Some parents described the consultative programs as taking place in the community, if related to their treatment goal. For example, Mrs. Hendrickson described working with her son and an educator at the park, or near their home on an intervention to decrease elopement.

Table 2

Type, Intensity, and Duration of Public Treatment Services

Family	Type	Intensity	Duration
Rivera	IBI	20.0	06.0
Santos	Consultative	01.0	12.0
Hendrickson	Consultative	01.0	12.0
Lin	IBI	18.0	12.0
Vivas	Consultative	01.0	12.0
Kalou	IBI	18.0	18.0
Aknin	Consultative	01.0	12.0
Tanzir	IBI	18.0	18.0

Note. Intensity in hours per week and duration is months.

Some parents sought out services in the private sector. Table 3 outlines the specific services that parents selected. All five parents had selected ABA related intervention programs as the primary service for their children. The average intensity of these programs was approximately 14-hours per week, lasting an average of 4.8-months. As was the case for public services, parents also reported participating in other private programs, such as speech and occupational therapy. Some parents were able to access these private services through grants while others paid for them with their own money, resulting in considerable monetary strain and lifestyle changes. In both of these cases, the high cost of private treatment programs meant that their children had to experience a significantly lesser intensity and duration. The location of private services occurred at a center or in the child's daycare.

Table 3

Type, Intensity, and Duration of Private Treatment Services

Family	Type	Intensity	Duration
Rivera	ABA	6	3
Santos	ABA	20	3
Hendrickson	-	-	-
Lin	ABA	20	6
Vivas	-	-	-
Kalou	ABA	15	6
Aknin	-	-	-
Tanzir	ABA	10	6

Note. Intensity in hours per week and duration is months.

Perception of services. Immigrant parents discussed several aspects related to the treatment services that their children had been receiving. Two main themes emerged from the data: (a) services viewed as effective and (b) services providing emotional support.

Mrs. Rivera speaks of the IBI program that her son was attending (funded by the government) as being effective because they held meetings every month to discuss and present written documents outlining his success.

> We know our last meeting they told us about the socialization and frustration and … over 100% that the goals were. He has like 95%, 82%. That's progress. And we [do not] finish until October. We have more, obviously, more to do. But, they show us in paper, how they see that he, I mean, test him.

This parent frequently mentioned her appreciation for government services and perceived them as experts. When asked if she would ever say no to any offered services she responded:

> I say yes to everything. Everything. You know what, I came I came from a country that the government offered you nothing. Nothing. So you, and also I learned if somebody is

> offering you something, why not you have to say no.

Mrs. Kalou also expressed that she felt the IBI program was effective for her son, but that at first she did not understand all of their methodologies.

> So, at the beginning I found it, what are they doing? But, I found that it was effective, yes. Often, I would watch them and think why are they doing all of that, why are they going through all of that trouble for nothing, but then I said 'no, it works'. *[Translated]*

Mrs. Lin described the government IBI services to be so effective that she did not feel that she needed to supplement his learning at home.

> You know, in my experience the best service is very important. Since when he went to there I feel really relaxed. I feel I do not have to work 1-hour or 2-hour with him per day because I know he already have an intense work there. So I'm really relaxed after that. And he learn, his French improve a lot and he start…it's great.

Some parents reported that the programs provided them with emotional support. In particular, Mrs. Tanzir described her experiences with the CLSC child stimulation group:

> But for sure, me, personally, at the *[program]*, they helped us psychologically. Because of having to go every Wednesday to meet and then once a month they had a meeting just for parents, without the children and so they had each meeting, it was voluntary, there were a lot of volunteers that came. They selected a theme for the meeting, they tried, because it was hard to give parents a clear idea, but they tried to share experiences with us and others, talk about gluten-free diets, talk about school, what to do after schools, how they will grow up, problems at home, do yes, at the *[Center]*, it was often volunteers, not professionals. *[Translated]*

This idea that intervention is not just about the child, but also about the parents, seemed to give families a sense of being emotionally supported by the professionals in the program. Mrs.

Tanzir also described feeling very supported by the staff at the IBI program when she asked them to help her with a new diet that she wanted to try with her son.

> When you tell them that my child is following a diet, they are not going to stop and think too long on this question, they are just going to ask what the instructions are, and then they are going to following them precisely, for that, I take my hat off to them. The *[Program name]* really helped me at the beginning because it was in this program that I first started it, where I first started the diet and they really, really, really helped me at the beginning. *[Translated]*

Her response indicates that she was almost surprised by their non-judgmental collaboration with her goals for her son, but also, without a doubt, conveys her feelings of being supported, heard, and respected by the program staff.

Barriers to service. Immigrant parents reported numerous barriers to service, involving contextual and cultural elements, as well as more general systemic issues. The most common contextual and cultural barriers to service included language barriers and conflicting cultural practices. Mrs. Rivera described her difficulty integrating her child into a daycare, as teachers did not understand some of his idiosyncratic behaviors:

> He's trying to understand why people here don't hug, don't kiss each other, don't laugh a lot, … and I say '*[Child's name]* always if you want to hug them you have to ask, you have to, if you want to kiss them you have to ask first'. Because the, the, the teacher at that time say 'it's because he is very touchy, he wants to touch everybody' and I say 'well come on, I'm Latin, he is Latin American, I mean like, we are a peoples, people-we like to touch!' So, it's some culture, no? And also, it's that kind of culture that that, that we are living here, we need to learn about, about this kind of behave and we can have at home another kind of behave and we speaking in Spanish.

In the same way, language barriers were discussed as problematic to accessing and participating in services. Mrs. Lin described a disagreement that she had with a private service provider about what language she should be speaking with her son at home. Before beginning services, the mother had been speaking Mandarin with her son, as she was not able to speak French or English to him. The service provided, however, felt that it was important that the mother speak French to him at home in order to maximize his learning.

> She *[Service provider]* ask me talk with *[Child's name]* in French. I think my French is not good enough; I want to talk with him in Chinese. And she fight with me, she say I'm not a good parent. I say I have no choice. If he learn French with me it will be catastrophe. But they always say it's not good result because of you, because you do not let him learn the language.

In this case, the program approach and recommendations were not individualized to this family's needs. While increasing the child's opportunity to practice a language that he must learn would be beneficial, such a recommendation may not be realistic without considering the family's unique circumstances (e.g., lack of competence in a second language) and preferences.

The common systemic barriers to services included limited access to service, long waitlists, and lack of stability and link with other services. All immigrant parents described having to wait for public services, as was the case for the diagnosis. Due to the long waitlists and limited number of programs, for the diagnosis or intervention services, only half of the children from the sample were able to get into a government-funded IBI program.

The other systemic barrier, the absence of stability and links with other programs, was reported by Mr. and Mrs. Santos. They had described that they had just moved to another municipality and consequently were required to sign up at another CLSC. This transition, however, proved disappointing as they felt as though they were starting back at square one.

> M: But now we changed already since we move because before it was over there in CLSC

[municipality]. … And when we move here its other CLSC.

F: Different places different services. That's a problem why. But we're expecting them to pass the case like whatever place you go CLSC is like ok this is the profile take it. Were just wondering why?

Relationship with Professionals

Immigrant parents described numerous types and qualities of their interactions and relationships with professionals during the diagnosis and within treatment services for their children. These emerging themes included the context of their interactions and communication, parental involvement in treatment services, and parent perceptions of professionals.

Context of interactions/communication. Within the broad category of communication with professionals, three themes emerged from the data. These include: (a) methods of communication, (b) frequency of contact, and (c) accessibility of professionals.

Method of communication. Most interactions were described as occurring through daily communication books. After each session, the educators or therapists would briefly describe what activities were worked on, as well as report any pertinent successes or challenges. Overall, immigrant parents reported that they were pleased with this form of communication. When Mrs. Tanzir was asked what she thought of daily communication books she responded: "Perfect… . The therapists tried to report everyday how it went during the four hours that we left our children there, the positive and the negative side" *[Translated]*. The fact that there was a focus on the positive and negative aspects to report suggests parents may have appreciated the honesty and transparency and thus made this form of communication more meaningful.

The other main form of communication included scheduled observations of the child during therapy. Several parents reported the benefits of center observations, such as learning about the program and teaching techniques, observing their child's progress, and getting an opportunity to ask questions or report concerns to professionals. Mrs. Kalou reported learning of the program and meeting with professionals through frequent observations at the government IBI program: “Well, at *[Program name]* often they would ask us parents to assist, so it was like that, I assisted and I saw a little bit how it worked” *[Translated]*. Similarly, Mrs. Santos reported watching every session with an educator:

> Oh yeah, we’re watching. Cause it’s her time for an hour, so let them and we’re observing and after that she has the assessment after and, I mean, the recapitulation of what they’re doing after every session, and that’s what were also doing.

The final form of parent-professional communication was through formal meetings. Immigrant parents described having meetings with professionals of the service programs, to review goals, and discuss their child’s progress. In addition, these formal meetings served as a means for the parents to bring up any concerns or questions. Mrs. Tanzir recounted her experience of communicating and collaborating with professionals during formal meetings at the IBI program:

> There was always that meeting where they explained to us what they were going to do and they would always finish by asking us if we were in agreement, even if it was for his own good, and if the parent was not in agreement, something that rarely happened, but if we were not in agreement they would not apply the program, it was like that. *[Translated]*

In this example, it is clear that the parent-professional communication and interaction that occurred during the formal meetings was of a collaborative nature and as a consequence, regarded as highly valuable to parents.

Frequency of contact. The frequency of contact with professionals varied across parents as well as across the different programs that they experienced. In general, immigrant parents reported daily contact with professionals through more informal methods of communication, such as brief conversations at drop off and pick up, or through the home communication books. The more formal meetings and observations were reported to occur on a monthly basis. Some parents described professionals to be highly accessible and available to communicate when needed, even outside of scheduled meetings and observations. For example, when asked if it was easy to contact her son's educator, Mrs. Hendrickson replied: "Yes very easily. He gave me his cell number and his extension number so I always can find him".

Some immigrant parents, on the other hand, described only brief interactions either before or after the treatment session. As a consequence, they appeared to be less informed about their child's therapy and did not report characteristics of a collaborative relationship. For example, Mrs. Aknin described that she did not know what they were working on: "I don't really know what they are doing. I know just the educator, but I don't know her name, it's recent, it only just started" *[Translated]*. Also, Mrs. Hendrickson explained that she was not able to speak with educators about the program as there were too many people around at drop off and pick up: "There were like so many people, they were trying to get the kids inside, so I never really got to sit with them and talk about it". Mrs. Lin described her disappointment with the lack of contact with professionals at a private center her son had attended.

> For the *[Program name]*, in the beginning, they talk about how they will after 7-weeks, have a meeting for me and for the director. But I think I just talk with her 1 time, so I never meet with her again.

The parent's focus on the private service provider's inability to follow through on her word suggests a lack of trust and absence of a collaborative relationship. This was not conducive to building trust and a relationship with the family.

Parental involvement in services. Within the broad category of parental involvement in services, the following two main themes emerged: (a) direct involvement in services and (b) indirect involvement in services.

Direct parental involvement. Immigrant parents described several different forms of direct parental involvement in their children's treatment services. One of these forms included working in collaboration with professionals to establish goals and implement the necessary teaching procedures in order to achieve those goals. When asked what goals the educator was working on with her son, Mrs. Vivas explained: "Because I ask *[Educator]* that my priority and goal for *[Child's name]* is to know how to communicate. So that is the goal". She then went on to say that she enjoyed participating during the therapy session: "Because sometimes other parents, they are outside watching them in the mirror but I'm comfortable when I'm in the room". Other parents described not participating as actively during the actual therapy session, but working on implementing the strategies at home. For example, Mrs. Tanzir recounted the details of her active involvement with the government treatment program her son attended.

> So my role was to observe at the center, be up to date on what happened, even day-by-day, it was most important to continue at home, it's what permitted for a continuity of services, and to bring in questions, if even I had difficulty applying or I noticed new behaviors that emerged. I would always come in and see the supervising staff members and then we would try and work on it. *[Translated]*

While these examples of active forms of parental involvement permitted for these immigrant parents to have an important role in the child's treatment, other parents did not participate as much.

Indirect parental involvement. Many of the parents reported their involvement to be less frequent and less implicated. Several parents described their role in the treatment as the transporter, responsible for dropping off and picking up their children. For example, Mrs. Rivera coined herself as “The taxi driver of my house” when talking about her responsibility of driving her son to his therapy every day. The other main indirect role that parents reported was to be insistent on obtaining services. Mrs. Aknin shared some advice on the importance of this role: “You can never give up, you should never quit, you have to keep looking, because no one is going to look for you. You always have to make the first move” *[Translated]*. Here, it is clear that the mother’s focus was not on the services that her daughter was getting at the moment, but always looking to secure more services for the future.

Positive perception of professionals. Most parents reported positive attributes and characteristics when discussing professionals. Common themes include: (a) professionals as experts and (b) warm and caring.

Professionals as experts. In general, most immigrant parents described the professionals that they encountered as experts. Some parents looked to the expertise of these professionals they encountered as having the answers to their concerns and questions. This was evident across families, as they did not often seek out other experts, but expected the ones they were working with to give them the answers to their concerns.

> First of all I believe that when you have that kind of vocation and you feel like you are strong enough to help kids disabilities, or kids differences, or call them whatever you want, and you go to the school and you learn, and you read, and you practice, and you’re seeing what is everything, what kind of test or therapies can help them… and I call that when you are an expert. And you graduate and you study and you practice. (Mrs. Rivera)

Other parents alluded to their perceptions of professionals as experts through various comments related to their effectiveness and qualifications. For example, when Mrs. Vivas was unsure of whether the problems she had identified with her son before the official diagnosis were warranted or not, she was adamant on getting an expert opinion from the doctor: “I just waiting for the doctor, you know, to tell me. And I know you’re the doctor, you’re good, you studied for very long time, so”.

Professionals as warm and caring. Several parents had positive experiences with many of the professionals (e.g., educators, private psychologists) they had encountered. Typically, the theme of professionals as warm and caring was attributed to educators. For example, Mrs. Vivas said:

> *[Educator’s name]* is very supportive to *[Child’s name]*. She’s very loving. I know that every educator is like that because in *[Another center]* it’s like that. It’s the same, so maybe they are… that is their profession. So they are loving and patient. Takes a lot of patience because, you know, teaching the kids like that or, you know, it’s hard. It’s really hard.

Mrs. Rivera described her appreciation for a professional at a private clinic because she was warm and caring towards her and her son.

> That kind of mentality, let’s say kind of talking to me, as a real human mother. You know, so after that when I arrive, it was another kind of a meeting, *[Director’s name]* is a very brilliant woman, she has a lot of knowledge, she has that vocation, she tries to understand also not just the child, but my side, the parent’s side.

Clearly these attributes are important to Mrs. Rivera, as she described earlier, her Latin culture is warm and affectionate: “I mean like, we are a peoples, people-we like to touch”.

Negative perceptions of professionals. Some immigrant parents, however, indicated they held a more negative perception of professionals. Themes identified were: (a) professionals lacking vocation and (b) professionals not supporting families’ needs.

Professionals lacking vocation. Several immigrant parents reported that some of the professionals that they encountered lacked the passion and motivation to be efficient at their jobs. Mrs. Rivera described her frustration with some educators at a daycare:

> Sometimes I feel, like frustrated because it's incredible that kind of ignorance, I call that. Even for the people, I mean, not just for the people, for the teachers, it's incredible, they don't want to move an extra finger because nobody going to pay for it, … . if you are educator, you will not even, in these times, you will not expect that your group is going to be perfect. There is not perfect anymore.

Another parent described her experiences with private services providers: "But I think they are like a business, you know? It's not services - its business… she not listen to me and she always ask me to listen to her" (Mrs. Lin). These examples demonstrate that some parents perceived professionals to be inadequate for the roles that they were entrusted to fulfill.

Professionals not supportive of families' needs. Themes related to professionals not being supportive to families' needs often emerged when parents were discussing their interactions with doctors. Mrs. Hendrickson described her frustration when her pediatrician was not receptive to her worries about her son: "His pediatrician was really not understanding my feelings". Mrs. Tanzir commented on the lack of psychological support that pediatricians provided following the diagnosis: "This pediatrician would just talk about the medical side of things, say 'its autism, you have to accept it, it is never going to change, will never change and the child will need therapy' and then he stops there" *[Translated]*. These comments were very challenging for immigrant parents who did not have a way of assessing the accuracy of these statements and did not feel that medical professionals were sensitive to their feelings and needs as a family.

Future Expectations

Immigrant parents described several themes related to their future expectations for their children. Some common themes included their desire for their child to be autonomous, to integrate socially, and to no longer have the label of autism. For example, Mr. Santos described: "That he can be on his own. Yeah, that he can be at the same child with the same age. He overcome his delay". Mrs. Kalou also expressed this hope of losing the diagnosis:

> So me, in the future, I would like my children to become normal children. I don't know when exactly we are going to finish with everything, the therapy, services all over the place, but my wish is that at the end they will be perfect, they will both be perfect.

Similarly, when Mrs. Lin was asked what she hoped for her son in the future she responded:

> Independent; find something he like. Is not like, he like to do and he could do, and for this things he could support his life, also. Now it silly idea, but I wish … he can find some things he like to do, and he could do, and he could work on it also.

Interestingly, Mrs. Lin focused on her son attaining a career or occupation that will support his life, albeit one that he enjoys. This is reflective of her description of the focus that her parents put on her when she was young to succeed in school and secure a career.

For many immigrant parents in this study, however, it was not possible to articulate clear future expectations, as there remained a lot of uncertainty. Mrs. Aknin said: "I don't have any idea, we live just for today; we can't know what will happen in the future" *[Translated].*

Discussion

The broad purpose of this qualitative study was to understand how immigrant parents give meaning to their lived experiences with obtaining an ASD diagnosis and services for their children. Through in-depth, semi-structured interviews, each family shared their unique account of obtaining the diagnosis, treatment services, their relationship with professionals, and their future expectations for their children. Overall, immigrant parents reported a mix of positive and negative experiences related to the process of obtaining a diagnosis and services for their children with ASD. As reported in the literature, the findings from this study suggest that the process of obtaining a diagnosis and services is complex and challenging for immigrant families (Jegatheesan et al., 2010; Keenan et al., 2010).

The use of an eco-cultural framework (Super & Harkness, 1986), both in the data collection system and in the data analysis process, permitted for a deeper understanding of their beliefs and perceptions related to these experiences. Although each family followed their own path to obtaining the diagnosis and services, several common themes emerged. Specifically, several of the themes were related to a family's specific contextual and cultural foundations. Other themes related to various systemic issues that immigrant parents encounter as they try to navigate the process of obtaining a diagnosis and services in Montreal.

Contextual and Cultural Elements

This study clearly demonstrates the benefits of using an eco-cultural framework when working with diverse families. The developmental niche framework facilitates understanding and analyzing, cross-culturally, how culture structures the early childhood environment and how this influences child development through the physical setting, customs of care, and the psychology of the caretaker (Super & Harkness, 1986). In this study, parents' unique contextual and cultural situations were explored by asking them various open-ended questions about their lives, such as their experiences growing up in their home countries, child rearing practices, their daily routines, and their current support network. Much of the information that families shared in response to these questions allowed for a context with which to make meaning of their beliefs and perceptions related to their children's ASD diagnosis and services. For example, when exploring the theme of parents as advocates for obtaining services, it was clear that one mother's background of growing up in Mexico City was relevant. Specifically, she discussed how Mexico City was such as large metropolis, fraught with government corruption, continuously forcing people to fight for their rights and services. When describing her upbringing she reflected on this experience and suggested that it could be a factor in why she naturally tends to be on the offensive when navigating the system in Montreal. In this case, without knowledge of her background and beliefs, her actions as advocate, such as actively calling, questioning, and demanding more from service providers and professionals, may be misinterpreted and compromise the delicate parent-professional relationship.

In relation to the diagnosis, it has been suggested that parental beliefs about the cause of autism is linked to their beliefs about treatment (Dale et al., 2006). While the current study found that parental beliefs about the cause of autism varied across parents, in some cases it was clear that immigrant parents' beliefs about cause were related to their beliefs about treatment. Mrs. Tanzir described her beliefs about the cause of ASD to be related to poor diet and vaccines. While she did not refuse the educational and behavioral support programs offered by the government, she was not surprised that they were not effective in producing the desired outcomes. As such, she was primarily devoted to improving her son's physical health through a strict gluten and casein-free diet. She believed that if she could cleanse his body of toxins and provide him with all of the nutrients that he needed, he might only then be more receptive to educational and behavioral programs. When describing her upbringing in Algeria, she focused on how her mother was devoted to preparing her family healthy, non-industrial foods, which she remarked, was different from many families here in North America, thus making her views on biomedical causes understandable. Again, this specific information on parental beliefs is an important factor to consider for optimal treatment adherence and sustainability (Lea & Moes, 2000).

One surprising finding of this study was that some mothers blamed themselves for their child's diagnosis. One mother believed that she was the cause for her daughter's ASD because she put her into daycare at the age of 7-months. Another mother believed that her son's diagnosis was caused by her feelings of sadness during the pregnancy. Unfortunately, this attribution of cause by mothers of children with ASD is not uncommon (Dale et al., 2006; Langan, 2011; Neely-Barnes et al., 2011), further supporting the need for professionals to investigate each parent's unique beliefs about autism before any treatment or services commence. It is even more complex with immigrant families, whose beliefs may be contextualized by their diverse cultural beliefs and expectations that are not always consistent with North American culture.

Another common contextual and cultural element to consider from the present study was in relation to language barriers to service. Many of the parents reported difficulty understanding and communicating with professionals due to their or their child's respective language barriers. Such problems arose throughout the process of obtaining a diagnosis as well as with treatment services. For example, Mrs. Rivera described her frustration with how the diagnosis was conducted. Even though she had explained to the professionals that her son only spoke and understood Spanish, the evaluations were conducted in English without the use of an interpreter. Likewise, another mother described that a professional was pressuring her to speak French with her son at home even though she was unable to speak French herself. Such examples suggest that professionals do not always consider a family's needs and the impact of language barriers. There were also nonverbal communication challenges that one parent experienced, explaining that her son was told that he was too affectionate (e.g., Latino culture) and this may have interfered with his progress in reading social cues. This form of operating from a North American perspective indicates that the professionals may often adhere to a more prescriptive approach to treatment as opposed to the more desirable contextualized approach that considers a family's unique context and needs in treatment planning (Moes & Frea, 2000). The families seem to be aware of this, but may feel powerless to speak up and advocate for themselves in this new country and service system (Lindsay, King, Klassen, Esses, & Statchel, 2012).

Another common theme, which emerged from this study's data analysis, reveals that these immigrant parents in Montreal seemed to lack an informal social support network. Almost all parents in the study discussed the difficulty with living apart from virtually all of their family, particularly when dealing with the challenges of raising their children with ASD. A study by Moodie-Dyer, Joyce, Anderson-Butcher, and Hoffman (2014) helps to shed light on the significance of this. Using a similar qualitative methodology as the present study, Moodie-Dyer and colleagues (2014) interviewed a sample of 19 parents of children with ASD from the Midwest, United States. One theme that emerged from their data analysis suggested that parents actively employed accessing their social support network as a coping strategy to the stress and challenges of raising children with ASD. Unfortunately, for many of the parents in the current investigation, this coping strategy is not as feasible as much of their family lived abroad. In addition, three mothers were single parents. Luong, Yoder, and Canham (2009) confirmed the reality of this concern with their qualitative investigation of a group of Southeast Asian immigrant families, living in Northern California. In-depth interviews were conducted to learn about their respective coping styles following their child's ASD diagnosis revealing that many parents were initially passive and in denial about the diagnosis as they felt a lack of support from family and professionals and as a consequence, did not understand the significance of the diagnosis. Hence, professionals should consider this problem of limited support network and create opportunities for immigrant parents to build a social network in Montreal or be sensitive to the impact of a diagnosis on these families, providing them with occasions to discuss and express their feelings openly.

Overall, given that Montreal is such a highly multicultural metropolitis (Statistics Canada, 2007) it is important that professionals recognize how parental beliefs about the diagnosis could contribute to their process of selecting and participating in treatment programs (Dale et al., 2006). Similarly, treatment objectives and services that meet the needs of families may be more sustainable to implement (Lea & Moes, 2000). Data from this qualitative study support these claims, emphasizing the importance of adopting a culturally responsive practice when working with families by considering families' perceptions and the core meaning of their experiences (Harry, 2002). That is, ensuring that parents are given a voice, understanding how their perceptions may be formed, and revisiting any relevant problems that may interfere with the negotiation of services. In addition to these contextual and cultural considerations, various systemic issues should be explored.

Systemic Issues/Barriers

The systemic issues that emerged from this study's interviews with immigrant families included long wait lists and the lack of continuity and stability between services and professionals. Overall, these findings are reflective of the various systemic issues discussed in the literature (Glazzard & Overall, 2012; Moodie-Dyer et al., 2014) and in particular for immigrant families (Jegatheesan et al., 2010).

The most common theme mentioned by all immigrant families included the long wait lists for both the diagnosis and intervention services. Some immigrant parents reported waiting as much as two years for a diagnosis and services, resulting in missed opportunities for entering into a government-funded IBI program. In Quebec, children under the age of 6-years-old, who have a diagnosis of ASD are entitled to 20-hours of IBI services at their local rehabilitation center (Quebec Ministry of Health and Social Services, 2003). Only half of the families from the present study had the opportunity to attend an IBI program. In addition to the inadequate amount of services, other factors may have delayed immigrant families' entry into services even further, such as denial of the diagnosis, lack of a support network, and difficulty navigating the system to identify services (Jegatheesan et al., 2010; Luong et al. 2009). Nevertheless, the experience of waiting for services, without having any influence on the outcome, could result in elevated parental stress, a feeling that critical teaching time had been lost, and a general frustration with the system (Glazzard & Overall, 2012).

In the current study, parents reported a lack of service stability and continuity. For example, one family described their frustration with having to retell their story and request services anew, compounded by trying to express themselves in a second language, after moving to another municipality. Similarly, Mrs. Kalou had two children diagnosed with ASD and as a result of moving to a new municipality, each of her sons were serviced by different agencies. This felt fragmented due to the immense difference in the quality and accessibility of the two services, Mrs. Kalou regretted having to move as she felt that her younger son did not get as good of a service as her older son. Mrs. Tanzir questioned altogether why IBI services were offered as the primary treatment for children with ASD under the age of 6-years-old. While she was grateful for the support, once the program was completed it became evident to her that this teaching approach was not utilized in any other program. For example, she suggested that since her son was exposed to a completely different teaching approach at school and daycare that perhaps instead of IBI services children should be exposed to a more natural approach to teaching that could be sustained in schools and daycares. While unfortunately these complaints are common to many parents in Quebec, with a large representation of immigrant families, suggesting a need to address this lack of coordination and consistency among services (Le Protecteur du Citoyen, 2009), immigrant parents may find it more challenging owing to their integration into a new society and having to learn the role of advocacy for their children with special needs. Due to the challenges that immigrant parents face while learning to navigate this new system (Jegatheesan et al., 2010) they may not be in a position to mediate between services, or ensure a smooth transition across services and therefore, this is a responsibility that professionals should assume by utilizing an individualized approach that considers the children's and families' individuals needs (Harry, 2002).

It is evident that adopting a culturally-responsive practice would assist professionals in better meeting the needs of families undergoing the process of obtaining a diagnosis and services for their children. This would, however, not be possible without examining and responding to the existing systemic issues and barriers that may be enhanced when families are also from diverse backgrounds. An improvement in these issues would make a culturally responsive practice more viable.

Limitations and Future Directions

While this qualitative study contributes to the paucity of literature on immigrant parents' experiences in obtaining a diagnosis and services for their children with ASD in Montreal, several limitations should be considered. First, the sample size is small and therefore the findings are representative and transferable to these specific families' lived experiences. Future studies could consider a more diverse sample of families in order to obtain a wider scope of experiences or a homogeneous sample of families (e.g., immigrant families from one particular culture) to delve deeper into their unique and shared experiences.

Secondly, the data used for this study were exclusively obtained from parent interviews and not from any other source because we were interested in parents' perceptions and how they made meaning about these experiences. It would be interesting to consider the point of view of multiple stakeholders in future studies to further inquire into the systemic issues that professional's experience that may limit them from providing a culturally sensitive approach to service provision; for example, a similar study that includes conducting interviews with professionals that interact with the families. Similarly, a closer exploration of the structure and content of parent-professional meetings, including an examination of presented documents, would reveal important information as to the nature of the parent-professional relationship.

Implications for Practice

This phenomenological study on parent perceptions of the autism diagnosis and services contains several critical implications for practice. Overall, the findings from this study suggest that in general, professionals do not use a culturally responsive framework when planning services and conducting interactions with parents. Through the use of a culturally responsive framework, professionals can be more effective at meeting the needs of a diverse group of parents (Harry, 2002). This could in turn improve services for the child.

In consideration of all of the systemic issues that act as barriers to effective services, as this study illuminated, several changes could be considered to improve the overall diagnostic and treatment services for ASD. Responding to the problems with waitlists, limited services offered, and lack of continuity of services is essential. Given that such issues are unlikely to be solved promptly, it would be important, in the meantime, to give immigrant parents realistic information on the current state of our services in order to avoid misunderstandings and unrealistic expectations.

References

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders, Fifth Edition.* Arlington, VA, American Psychiatric Association, 2013. Web. Retrieved from http://www.dsm.psychiatryonline.org/

Baer, D. M., Wolf, M. M., & Risley, T. R. (1968). Some current dimensions of applied behavior analysis. *The Journal of Applied Behavior Analysis, 1*, 91-97. Retrieved from http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1310980/pdf/jaba00083-0089.pdf

Barbaro, J., & Dissanayake, C. (2009). Autism spectrum disorders in infancy and toddlerhood: A review of the evidence on early signs, early identification tools, and early diagnosis. *Journal of Developmental and Behavioral Pedicatrics, 30*, 447-459. doi: 10.1097/DBP.0b013e3181ba0f9f

Begeer, S., El Bouk, S., Boussaid, W., Terwogt, M. M., & Koot, H. M. (2009). Underdiagnosis and referral bias of autism in ethnic minorities. *Journal of Autism and Developmental Disorders, 39,* 142-248. doi: 10.1007/s10803-008-0611-5

Brantlinger, E., Jimenez, R., Klingner, J., Pugach, M., & Richardson, V. (2005). Qualitative studies in special education. *Exceptional Children, 71*, 195-207. doi: 10.1177/001440290507100205

Bronfenbrenner, U. (1979). *The ecology of human development: Experiments by nature and design.* Cambridge, Mass.: Harvard University Press.

Brookman-Frazee, L., Baker-Ericzen, M., Stadnick, N., & Taylor, R. (2012). Parent perspectives on community mental health services for children with autism spectrum disorders. *Journal of Child and Family Studies, 21*, 533-544. doi: 10.1007/s10826-011-9506-8

Casey, L. B., Zanksas, S., Meindl, J. N., Parra, G. R., Cogdal, P., & Powell, K. (2012). Parental symptoms of posttraumatic stress following a child's diagnosis of autism spectrum disorder: A pilot study. *Research in Autism Spectrum Disorder, 6*, 1186-1193. doi: 10.1016/j.rasd.2012.03.008

Centers for Disease Control and Prevention. (2012). Prevalence of autism spectrum disorders – Autism and developmental disabilities monitoring network, 14 sites, United States, 2008. *Morbidity and Mortality Weekly Report, 61*, 1-19. Retrieved from http://www.cdc.gov/mmwr/preview/mmwrhtml/ss6103a1.htm?s_cid=ss6103a1_w

Centers for Disease Control and Prevention. (2014). Prevalence of autism spectrum disorder among children aged 8 years -Autism and developmental disabilities monitoring network, 11 sites, United States, 2010. *Morbidity and Mortality Weekly Report, 63*, 1-21. Retrieved from http://www.cdc.gov/mmwr/preview/mmwrhtml/ss6302a1.htm

Coo, H., Ouellette-Kuntz, H., Lam, M., Yu, C. T., Dewey, D., Bernier, F. P., … Holden, J. J. (2012). Correlates of age of diagnosis of autism spectrum disorders in six Canadian regions. *Chronic Diseases and Injuries in Canada, 32*, 90-100. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/22414306

Cooper, J. O., Heron, T. E., & Heward, W. L. (2007). *Applied behavior analysis* (2nd ed.). Upper Saddle River, NJ: Pearson.

Creswell, J. W. (2012). *Educational research: Planning, conducting, and evaluating quantitative and qualitative research* (4th ed.). Boston, MA: Pearson Education.

Dale, E., Jahoda, A., & Knott, F. (2006). Mother's attributions following their child's diagnosis of autistic spectrum disorder: Exploring links with maternal levels of stress, depression and expectations about their child's future. *Autism, 10,* 463-479. doi: 10.1177/1362361306066600

Desai, M. U., Divan, G., Wertz, F. J., & Patel, V. (2012). The discovery of autism: Indian parents' experiences of caring for their child with autism spectrum disorder. *Transcultural Psychiatry, 49*, 613-637. doi: 10.1177/1363461512447139

Dillenburger, K., Keenan, M., Doherty, A., Byrne, T., & Gallagher, S. (2010). Living with children diagnosed with autistic spectrum disorder: Parental and professional views. *British Journal of Special Education, 37,* 13-23. doi: 10.1111/j.1467-8578.2010.00455.x

Elsabbagh, M., Divan, G., Koh, Y., Kim, Y. S., Kauchali, S., Marcín, C., … Fombonne, E. (2012). Global prevalence of autism and other pervasive developmental disorders. *Autism Research, 5*, 160-179. doi: 10.1002/aur.239

Englander, M. (2012). The interview: Data collection in descriptive phenomenological human scientific research. *Journal of Phenomenological Psychology, 43*, 13-35. doi: 10.1163/156916212X632943

Ennis-Cole, D., Durodoye, B. A., & Harris, H. L. (2013). The impact of culture on autism diagnosis and treatment: Considerations for counselors and other professionals. *The Family Journal: Counseling and Therapy for Couples and Families, 21*, 279-287. doi: 10.1177/1066480713476834

Epstein, J. L., & Dauber, S. L. (1991). School programs and teacher practices of parent involvement in inner-city elementary and middle schools. *The Elementary School Journal, 91*, 289-305. Retrieved from: http://www.jstor.org/stable/1001715

Fombonne, E., Zakarian, R., Bennett, A., Meng, L., & McLean-Heywood, D. (2006). Pervasive developmental disorders in Montreal, Quebec, Canada: Prevalence and links with immunizations. *Pediatrics, 118*, 139-150. doi: 10.1542/peds.2005-2993

Glazzard, J., & Overall, K. (2012). Living with autistic spectrum disorder: Parental experiences of raising a child with autistic spectrum disorder (ASD). *Support for Learning, 27,* 37-45. doi: 10.1111/j.1467-9604.2011.01505.x

Granger, S., Rivière-Pigeon, C., Sabourin, G., & Forget, J. (2012). Mothers' reports of their involvement in early intensive behavioral intervention. *Topics in Early Childhood Special Education, 32*, 68-77. doi: 10.1177/0271121410393285

Green, V. A. (2007). Parental experience with treatments for autism. *Journal of Developmental and Physical Disabilities, 19,* 91-101. doi: 10.1007/s10882-007-9035-y

Harry, B. (2002). Trends and issues in serving culturally diverse families of children with disabilities. *The Journal of Special Education, 36*, 131-138. doi: 10.1177/00224669020360030301

Harkness, S., Super, C. M., Sutherland, M. A., Blom, M. J. M., Moscardino, U., Mavridis, C. J., & Axia, G. (2007). Culture and the construction of habits in daily life: Implications for the successful development of children with disabilities. *OTJR: Occupation, Participation and Health, 27,* 33s-40s.

Herbert, E. B., & Koulougliotí, C. (2010). Parental beliefs about cause and course of their child's autism and outcomes of their beliefs: A review of the literature. *Issues in Comprehensive Pediatric Nursing, 33*, 149-163. doi: 10.3109/01460862.2010.498331

Hoge, N. & Runswick-Cole, K. (2008). Problematising parent-professional partnerships in education. *Disability and Society, 23,* 637-647. doi: 10.1080/09687590802328543

Hoover-Dempsey, K. V., Walker, J. M. T., Jones, K. P., & Reed, R. P. (2002). Teachers involving parents (TIP): Results of an in-service teacher education program for enhancing parental involvement. *Teaching and Teacher Education, 18*, 843-867. doi: 10.1016/S0742-051X(02)00047-1

Janus, M., Lefort, J., Cameron, R., & Kopechanski, L. (2007). Starting kindergarten: Transition issues for children with special needs. *Canadian Journal of Education, 30*, 628-648. doi: 10.2307/20466656

Jegatheesan, B., Fowler, S., & Miller, P. J. (2010). From symptom recognition to services: How South Asian Muslim immigrant families navigate autism. *Disability and Society, 25,* 797-811. doi: 10.1080/09687599.2010.520894

Keenan, M., Dillenburger, K., Doherty, A., Byne, 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. doi: 10.1111/j.1468-3148.2010.00555.x

Kim, H. U. (2012). Autism across cultures: Rethinking autism. *Disability and Society, 27*, 535-545. doi: 10.1080/09687599.2012.659463

Langan, M. (2011). Parental voices and controversies in autism. *Disability and Society, 26*, 193-205. doi: 10.1080/09687599.2011.544059

Lazoff, T., Zhong, L., Piperni, T., & Fombonne, E. (2010). Prevalence of pervasive developmental disorders among children at the English Montreal School Board. *The Canadian Journal of Psychiatry, 55*, 715-720. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/21070699

Le Protecteur du Citoyen. (2009). *Looking towards great continuity in service delivery, approaches, and human relations: Special ombudsman's report on government services for children with pervasive developmental disorders.* Retrieved from http://www.protecteurducitoyen.qc.ca/fileadmin/medias/pdf/rapports_speciaux/REPORT_TED-tr-rev.pdf

Lindsay, S., King, G., Klassen, A. F., Esses, V., & Stachel, M. (2012). Working with immigrant families raising a child with a disability: challenges and recommendations for healthcare and community service providers. *Disability and Rehabilitation, 34*, 2007-2017. doi: 10.3109/09638288.2012.667192

Luong, J., Yoder, M. K., & Canham, D. (2009). Southeast Asian parents raising a child with autism: a qualitative investigation of coping styles. *Journal of School Nursing, 25*, 222-229. doi: 10.1177/1059840509334365

Mackintosh, V. H., Goin-Kochel, R. P., & Myers, B. J. (2012). "What do you like/dislike about the treatments you're currently using?" A qualitative study of parents of children with autism spectrum disorders. *Focus on Autism and Other Developmental Disabilities, 27,* 52-60. doi: 10.1177/1088357611423542

Mandell, D. S., & Novak, M. (2005). The role of culture in families' treatment decisions for children with autism spectrum disorders. *Mental Retardation and Developmental Disabilities, 11*, 110-115. doi: 10.1002/mrdd.20061

Mandell, D. S., Wiggins, L. D., Carpenter, L. A., Daniels, J., DiGuiseppi, C., Durkin, M. S., … Kirby, R. S. (2009). Racial/ethnic disparities in the identification of children with autism spectrum disorders. *American Journal of Public Health, 99*, 493-498. doi: 10.2105/AJPH.2007.131243

McCabe, H. (2007). Parent advocacy in the face of adversity: Autism and families in the People's Republic of China. *Focus on Autism and other Developmental Disabilities, 22*, 39-50. doi: 10.1177/10883576070220010501

Merriam, S. B. (2009). *Qualitative research: A guide to design and implementation.* San Francisco, CA: Jossey-Bass.

Moes, D. R., & Frea, W. D. (2000). Using family context to inform intervention planning for the treatment of a child with autism. *Journal of Positive Behavior Interventions, 2*, 40-46. doi: 10.1177/109830070000200106

Moh, T. A., & Magiati, I. (2012). Factors associated with parental stress and satisfaction during the process of diagnosis of children with autism spectrum disorders. *Research in Autism Spectrum Disorders, 6*, 293-303. doi: 10.1016/j.rasd.2011.05.011

Moodie-Dyer, A., Joyce, H. D., Anderson-Butcher, D., & Hoffman, J. (2014). Parent-caregiver experiences with the autism spectrum disorder service delivery system. *Journal of Family Social Work, 17*, 334-362. doi: 10.1080/10522158.2014.903581

Mulligan, J., MacCulloch, R., Good, B., & Nicholas, D. B. (2012). Transparency, hope, and empowerment: A model for partnership with parents of a child with autism spectrum disorder at diagnosis and beyond. *Social Work in Mental Health, 10,* 311-330. doi: 10.1080/15332985.2012.664487

National Epidemiologic Database for the Study of Autism in Canada. (2012). Findings from the National Epidemiologic Database for the Study of Autism in Canada (NEDSAC): Changes in the prevalence of autism spectrum disorders in Newfoundland and Labrador, Prince Edward Island, and Southeastern Ontario. Retrieved from http://www.autismsocietycanada.ca/DocsAndMedia/KeyReports/NEDSAC_Report_March2012.pdf

Neely-Barnes, S. L., Hall, H. R., Roberts, R. J., & Graff, J. C. (2011). Parenting a child with an autism spectrum disorder: Public perceptions and parental conceptualizations. *Journal of Family Social Work, 14,* 208-225. doi: 10.1080/10522158.2011.571539

Norbury, C. F., & Sparks, A. (2013). Differences or disorder? Cultural issues in understanding neurodevelopmental disorders. *Developmental Psychology, 49*, 45-58. doi: 10.1037/a0027446

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

Ouelette-Kuntz, H. M. J., Coo, H., Lam, M., Yu, C. T., Breitenbach, M. M., Hennessey, P. E., … Crews, L. R. (2009). Age at diagnosis of autism spectrum disorders in four regions of Canada. *Canadian Journal of Public Health, 100*, 268-273. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/19722339

Poirier, A., & Goupil, G. (2008a). Perceptions des parents québécois sur l'annonce d'un diagnostic de trouble envahissant du développement. *Journal on Developmental Disabilities, 14*, 29-39. Retrieved from http://www.oadd.org/docs/JoDD_14-3_Poirier_2.pdf

Poirier, A., & Goupil, G. (2008b). Processus diagnostique des personnes présentant un trouble envahissant du développement au québéc: Expérience des parents. *Journal on Developmental Disabilities, 14*, 19-28. Retrieved from http://www.oadd.org/publications/journal/documents/JoDDPoirierfinalarticle1.pdf

Quebec Ministry of Health and Social Services. (2003). *Un geste porteur d'avernir. Des services aux personnes présentant un trouble envahissant du développement, à leur famille et à leurs proches.* Sainte-Foy, Québec, Canada: Government of Quebec. Retrieved from http://publications.msss.gouv.qc.ca/acrobat/f/documentation/2002/02-820-01.pdf

Ratajczak, H. V. (2011). Theoretical aspects of autism: Causes-A review. *Journal of Immunotoxicology, 8*, 68-79. doi: 10.3109/1547691X.2010.545086

Ravindran, N., & Myers, B. J. (2012). Beliefs and practices regarding autism in Indian families now settled abroad: An internet survey. *Focus on Autism and other Developmental Disabilities, 28*, 44-53. doi: 10.1177/1088357612458970

Solish, A., & Perry, A. (2008). Parents' involvement in their children's behavioral intervention programs: Parents and therapist perspectives. *Research in Autism Spectrum Disorders, 2*, 728-738. doi: 10.1016/j.rasd.2008.03.001

Statistics Canada. (2007). *Immigration in Canada: A portrait of the foreign-born population, 2006 census.* (Catalogue no. 97-557-XIE). Retrieved from http://www12.statcan.ca/census-recensement/2006/as-sa/97-557/pdf/97-557-XIE2006001.pdf

Steiner, A. M., Koegel, L. K., Koegel, R. L., Ence, W. A. (2012). Issues and theoretical constructs regarding parent education for autism spectrum disorders. *Journal of Autism and Developmental Disorders, 42,* 1218-1227. doi: 10.1007/s10803-011-1194-0

Stoner, J. B. & Angell, M. E. (2006). Parent perspectives on role engagement: An investigation of parents of children ASD and their self-reported roles with education professionals. *Focus on Autism and Other Developmental Disabilities, 21,* 177-189. doi: 10.1177/10883576060210030601

Stoner, J. B., Bock, S. J., Thompson, J. R., Angell, M. E., Heyl, B. S., & Crowley, E. P. (2005). Welcome to our world: Parent perceptions of young children with ASD and education professionals. *Focus on Autism and other Developmental Disabilities, 20,* 39-51. doi: 10.1177/10883576050200010401

Super, C. M., & Harkness, S. (1986). The developmental niche: A conceptualization at the interface of child and culture. *International Journal of Behavioral Development, 9,* 545-569. doi: 10.1177/016502548600900409

Yu, S. M., Huang, Z. J., & Kogan, M. D. (2008). State-level health care access and use among children in US immigrant families. *American Journal of Public Health, 98*, 1996-2003. doi: 10.2105/AJPH.2007.117911

Appendix A

INFORMATION LETTER TO DIRECTORS

UNIVERSITÉ
Concordia
UNIVERSITY

INFORMATION LETTER TO CLINICAL DIRECTORS AND SUPERVISORS

Dear Clinical Director(s)/Supervisor(s),

I am a graduate student in the Department of Education at Concordia University and this research is for my thesis, as a final requirement to complete my master's degree in Child Studies. I am interested in exploring how parents experience and perceive the diagnosis of their child with autism and the process of selecting and accessing services for their child. This research will be conducted under the direction of my faculty supervisor Dr. Hariclia Harriet Petrakos of the department of Education of Concordia University (telephone: 514-848-2424, ext. 2013; email: hpetrakos@education.concordia.ca*)*.

In order to conduct this research, I would appreciate your assistance in the recruitment process. I am looking to recruit **parents** according to the following selection criteria: (a) the parents will have a child with a diagnosis of ASD; (b) the child is, or has been attending an autism intervention program; (c) the child is 6-years-old or younger; and (d) the child has at least one parent that has been residing in Canada for 10-years or less.

Participants will be given a short questionnaire, as well as participate in an in-depth interview that will take approximately 90-120 minutes, and a short follow-up interview. After all of the interviews are complete, a parent workshop, dedicated to discussing ASD resources and related topics, will be offered.

I have attached the parent information letter and release form that will provide you with additional information about the research project. Please share copies with any parents that meet the selection criteria. Should parents wish to participate, please instruct them to return the signed release form to you, for me to collect and proceed in contacting them via telephone to further discuss their interest and participation in the study.

Your support and guidance in recruiting parents to participate in this research project would be greatly appreciated.

If you have any questions or concerns, please do not hesitate to contact me (telephone: 514-961-1436; email: k_donald@education.concordia.ca), or my faculty supervisor Dr. Hariclia Harriet Petrakos (telephone: 514-848-2424, ext. 2013; email: hpetrakos@education.concordia.ca).

Thank you in advance,

Kristina Donald, M.A. Thesis Candidate (Child Studies)
Department of Education
Concordia University

Appendix B

CONSENT TO CONTACT FORM

UNIVERSITÉ
Concordia
UNIVERSITY

PARENT CONTACT RELEASE FORM

I consent that my name and phone number(s) be released to the researcher, Kristina Donald, and that the researcher contacts me to discuss my participation in the study described in the information letter.

NAME (please print) ____

TELEPHONE (Home) ____

TELEPHONE (Cell) ____

TELEPHONE (Work) ____

SIGNATURE ____

Thank you for your consideration. If you have any questions or concerns, please feel free to contact me, Kristina Donald at 514-961-1436, or my supervisor Dr. Harriet Petrakos at 514-848-2424 ext. 2013.

Sincerely,

Kristina Donald, M.A. Thesis Candidate (Child Studies)
Department of Education
Concordia University

Appendix C

PARENT INFORMATION LETTER

UNIVERSITÉ
Concordia
UNIVERSITY

INFORMATION LETTER TO PARENTS

Dear Parent(s)/Guardian(s)

I am a graduate student in the Department of Education at Concordia University and this research is for my thesis. I am interested in exploring how parents experience the process of diagnosis of ASD and the services for their children.

We are looking for 10 parents whose child was diagnosed with Autism Spectrum Disorder (ASD) and is under the age of 6-years-old and is attending an autism intervention program. When you consent to participate in this study, we will give you a short questionnaire and conduct an interview with you that will take approximately 90-120 minutes. During this time, we will ask you questions about your child's diagnosis and intervention services. If you are not comfortable with speaking English or French, we will provide you with a translator for the interview. The entire interview will be audiotaped. A short follow-up interview, either in person or by telephone, will be done to ask you to clarify or elaborate on what you talked about during the first interview. After all of the interviews are complete, a parent workshop, dedicated to discussing ASD resources and related topics, will be offered.

All of the information in this study will remain confidential and your name and child's name will not be included in the final report. At the end of the study, we will give you a short summary of your comments during the interview, as well as ask your permission to use quotes in the final thesis.

A benefit of participating in this study is that it could allow you to explore your views and beliefs about your child's diagnosis and services. It also gives you an opportunity to gain information on and discuss ASD resources.

Thank you for your consideration. If you have any questions or concerns, please feel free to contact me, Kristina Donald at 514-961-1436, or my supervisor Dr. Harriet Petrakos at 514-848-2424 ext. 2013.

Sincerely,

Kristina Donald, M.A. Thesis Candidate (Child Studies)
Department of Education
Concordia University

Appendix D

PARENT CONSENT FORM

CONSENT FORM TO PARTICIPATE IN RESEARCH

I understand that I have been asked to participate in a research project being conducted by Kristina Donald, under the supervision of Dr. Hariclia Harriet Petrakos of the department of Education of Concordia University (telephone: 514-848-2424, ext. 2013; email: hpetrakos@education.concordia.ca*)*.

A. PURPOSE

I have been informed that the purpose of the research is to learn how about parents experience and perceive the diagnosis of their child with autism. Also, the researchers want to learn how parents make decisions when they select and access support services for their children with autism (ASD).

B. PROCEDURES

- I understand that I will participate in a one-on-one interview for this study, which will take place in a quiet location of my choice (e.g., home, university research office).
- I understand that the interview will last about 90-120 minutes and will be audio-recorded.
- I understand that before the interview, I will be asked to fill-out a short form about general information on myself and my family that will take no longer than 10-minutes to complete.
- I understand that if I prefer to have translation services, I will be provided with this service.
- I understand that I will be contacted for another short interview (no longer than 30-minutes) by telephone to clarify some answers or to provided some additional information that would be required for the study.
- I understand that I will be asked permission to use any quotes from my interview in the final report and thesis.
- I understand that all information that I share during the study will be kept confidential by not including names or identifying information in the final report and thesis.

C. RISKS AND BENEFITS

- I understand that the risks associated with participating in this study may include intense emotional feelings regarding the diagnosis and discussing topics related to my child and parenting.

- I understand that if I experience distress during my participation in this study, I can contact Dr. Harriet Petrakos (514-848-2424 ext. 2013), who is the faculty supervisor and a licensed psychologist and she will provide me with the appropriate resources.
- I understand that participation in this study could allow for an opportunity to explore my views and experiences regarding my child's diagnosis and services and may result in learning about additional resources and support services in my community.

D. CONDITIONS OF PARTICIPATION

- I understand that I am free to withdraw my consent and discontinue my participation at anytime without negative consequences. **Should I choose to withdraw my consent the information I provided will be deleted.**

  - I understand that the investigator does not promise that my child or I will benefit from the study. A benefit may be to express my views about the diagnosis and services of autism and to obtain some information on resources in my community.

- I understand that my participation in this study is CONFIDENTIAL (i.e., the researcher will know, but will not disclose my identity). All information I share will be kept confidential and private, unless the investigator thinks that the children are unsafe in any way. In that case, the research team has the obligation to report their concerns to the appropriate authorities.

- I understand that the data from this study may be published, however, no names or identifying information will be associated with the findings. The investigators will ask my permission if they decide to use quotes in the final report of the study.

I HAVE CAREFULLY STUDIED THE ABOVE AND UNDERSTAND THIS AGREEMENT.
I FREELY CONSENT AND VOLUNTARILY AGREE TO PARTICIPATE IN THIS STUDY.

NAME (please print) ____

SIGNATURE ____

If at any time you have questions about the proposed research, please contact the study's graduate masters' student and investigator Kristina Donald (telephone: 514-961-1436; email: k_donald@education.concordia.ca) or her supervisor and investigator, Dr. Hariclia Harriet Petrakos of the Department of Education of Concordia University (telephone: 514-848-2424, ext. 2013; email: hpetrakos@education.concordia.ca). If at any time you have questions about your rights as a research participant, please contact the Research Ethics and Compliance Advisor, Concordia University, 514.848.2424 ex. 7481 ethics@alcor.concordia.ca

Appendix E

PARTICIPANT DEMOGRAPHIC INFORMATION FORM

Parent A: ☐ Mother ☐ Father ☐ Legal guardian ☐ Other _________

1. Place of birth: ____
2. First language: ____
3. Language(s) spoken at home:
   ____
4. Highest level of education obtained:
   ____
5. Occupation: ____
6. Culture/Religion: ____
7. How long have you been living in Montreal?
   ____

Parent B: ☐ Mother ☐ Father ☐ Legal guardian ☐ Other: __________

1. Place of birth: ____
2. First language: ____
3. Language(s) spoken at home:
   ____
4. Highest level of education obtained:
   ____
5. Occupation: ____
6. Culture/religion: ____
7. How long have you been living in Montreal?
   ____

Child: ☐ Boy ☐ Girl

1. Date of Birth (MM/DD/YY): ______________________________

2. Place of birth: ____

3. What diagnosis does your child have?
   ____

4. Where was the diagnosis obtained?
   ____

5. Age of child at diagnosis?
   ____

Program: ☐ Public ☐ Private

1. Name of program: ____

2. How long has your child been attending the program?
   ____

3. How many hours per week does your child attend the program?
   ____

4. How much longer do you intend to have your child attend the program?
   ____

Appendix F

PARENT INTERVIEW PROTOCOL

Date & Time: _________________ Location: _________________

Interviewer: __________________ Interviewee(s): ______________________

Before beginning the interview, I would like to thank you for your participation in this study on parent experiences with ASD diagnosis and services. More specifically, I am interested in your experiences with learning about your child's ASD diagnosis and subsequently obtaining intervention services. I am interested in finding out how you experienced these events and what they mean to you. I would like to remind you that you are not obligated to answer a question if you do not wish, but that everything you say will be kept confidential and that you are free to withdraw from the study at any time. Do you have any questions before we begin?

EXPERIENCE WITH DIAGNOSIS

1. Tell me about the process involved in obtaining your child's ASD diagnosis by explaining all of the steps that you experienced from the first concerns to the official diagnosis and what this meant to you.

   PROMPTS:
   - *What were you thinking when you went through this process?*
   - *When and why did you notice that he/she was different?*
   - *Who did you speak to about your concerns?*
   - *What age was your child?*
   - *How many professionals did you communicate with during this process?*
   - *What was the final meeting like?*

2. Next, I would like to understand how you reacted to the process of obtaining a diagnosis and the experience of learning about your child's diagnosis?

   PROMPTS:
   - *How did you feel when the process was underway? Why did you feel this way?*
   - *How did you feel when the diagnosis was finalized? Why did you feel this way?*

3. If you could change anything about how the diagnostic process unfolded for your child, what would it be and why?

4. Can you describe some moments, during the diagnostic process, where you were unsure of what to do, or had difficulty understanding terms? Why did this happen?

   PROMPT:
   - *What did you do and why?*

5. Tell me about some moments when you felt that professionals helped you?

6. If you had to give advice to parents who were experiencing this process for the first time, what would you say to them?

BELIEFS ABOUT ASD

7. What does autism mean to you?

PROMPTS:
- *Cause?*
- *Treatment?*

8. Tell me about how you came to those beliefs?

PROMPTS:
- *How did you learn about the cause of autism?*
- *How did you learn about treatments?*

9. What do you think others believe about autism?

PROMPTS:
- *Immediate family?*
- *Extended family?*
- *Community members?*

HOME CONTEXT

10. Can you describe your daily routine with *[Insert child's name]*? What is it like to parent *[Insert child's name]*?

PROMPTS:
- *Tell me about things that go well at home and why.*
- *Are there any challenges? Why are these challenges occurring?*
- *What helps him/her at home?*
- *What would you like to improve and why?*

11. Describe what role you take on with *[Insert child's name]*? How would you describe your role as a parent?

PROMPTS:
- *Do you have other roles? Such as teacher? Tell me what this means to you?*
- *Can you compare it with other family members?*
- *Can you compare it with the individuals that work with him at the [Insert program name] program?*

FAMILY CONTEXT

12. It says here that you were born in *[Insert country name]*. Can you tell me about your experiences growing up there (and what did they mean to you)?

PROMPTS:

- *Physical setting (i.e., small town, city, village, close to family)?*
- *Child rearing practices (i.e., what was important to your parents, expectations)?*
- *Parental roles?*

13. How does your culture /background help you with your parenting or the other roles you that have with your child? Can you give an example?

PROMPTS:

- *What does it mean to you and your family to support [Insert child's name]?*
- *How would you compare your views and practices to other parents in Montreal or other families you know in your community? Can you give me an example of what is the same and what is different?*

INTERVENTION PROGRAM

14. Can you tell me about the *[Insert program name]* program that your child attends?

PROMPTS:

- *How did you find out about it?*
- *What approach to learning do they utilize? How do they support [Insert child's name]?*
- *Why did you choose this program?*

15. Can you tell me a little bit about the people that work at the *[Insert program name]* program?

PROMPTS:

- *How many people work with your child?*
- *Who is responsible for creating and overseeing the progress of program goals?*
- *How often do you speak/interact with each of those people?*
- *What kind of qualifications do they have?*
- *What does it mean to you to work with them?*

INTERVENTION PROGRAM GOALS

16. Let's go back to what help your child is receiving. What goals are they working on at the *[Insert program name]* program?

PROMPTS:

- *How did you learn about these goals?*
- *How is he/she doing with the goals?*
- *How long have they been running these goals?*
- *What do you think of the way they are work with him/her?*

17. What role did you have in choosing the goals they are working on? How did you find out about them? Can you describe how each of the goals was established?

PROMPTS:

- *Through assessment?*
- *Discussion about parental concerns?*

18. Can you tell me what you think of the goals?

PROMPTS:

- *What do you like?*
- *What don't you like?*
- *If you had all the freedom to choose, what do you think they should be working on?*

RELATIONSHIP WITH PROFESSIONALS

19. Tell me about your interactions with *[Insert name of person responsible for establishing and overseeing program goals]*? What does it mean to you to work with them?

PROMPTS:

- *How often do you interact?*
- *Is this person easy to get a hold of?*

20. How do you feel when you communicate with *[Insert person's name] and why*?

PROMPTS:

- *What do you like?*
- *What don't you like?*

PARENTAL INVOLVEMENT

21. Tell me about the meetings that you have at the center?

PROMPTS:

- *Who is present?*
- *How often do they take place?*
- *What do you discuss?*
- *Do you feel comfortable expressing your opinions, concerns, and needs?*
- *What would you improve about the meetings?*

22. Tell me about how you, or other family members, participate in your child's therapy?

PROMPTS:

- *Observations at the center?*
- *Therapy conducted at home/participate in therapy?*
- *Formal training in interventions?*

- *Reading of materials/seeking information at home?*
- *Collaborate to make decisions about goals/programs?*

23. How do you see your role in the program?

PROMPTS:
- *What do you like about this role?*
- *What would you change about?*

FUTURE EXPECTATIONS

24. What are your future expectations for your child?

PROMPT:
- *What led you to that view?*

25. How would your expectations be different if your experiences were different?

Appendix G

DATA ANALYSIS CODING SCHEME

Category	Broad themes	Sub-themes

Identification of the problem	Who identifies problem? Context?	Parent, Family, Daycare worker, Social worker, Pediatrician
	What were the signs?	ASD related symptoms, sensory sensitivity, problem behaviors.
	Denial/Disagreement/ Doubt	Pediatrician, Mother, Father, Relatives, Other professionals, Friends, Mother is too discouraged to go through process, Believes that it is just a delay.
	What was the diagnosis/preference?	ASD to obtain code/services, Language delay, Hearing problem.
	Experience with diagnostic process	Inappropriate questions/format, Difficulty understanding steps in process, Difficulty understanding terms/abbreviations, Questions not relevant, Language barriers
	Location	Private, hospital, government funded developmental community center,
	Who gave final diagnosis?	Multidisciplinary team, Pediatrician, Psychologist, Psychiatrist
	What was final diagnosis	ASD, Severe, moderate, PDD-NOS, To be determined after subsequent testing in future,
	Reaction to final diagnosis	Sad, Cry, Uncertain/Concerned of the future, Predicted it, Guilty, Doubting herself, Difficult to accept, Lives are about to become more complicated with two children with diagnoses, Disagreement with spouse, Upset and confused, Unable to speak or ask questions, Shock, Regret that it was not done sooner, Disagree with final diagnosis, Life will end as all focus will have to be on taking care of child.
	Coping strategies/acceptance	Religion,
Beliefs about ASD	What does it mean?	Child lives in another world, Child experiences life of suffering, Sickness, Child is different, Child is special, Child is lacking social/communication/motor skills, Temporary/may grow out of it, Lifelon
	How are beliefs formed?	Internet, Books, Family, Community, Friends, Dictionary, Professionals, Other parents with children with ASD
	Causes	No genetic component, Biomedical causes, Mother's fault, Poor diet during pregnancy, Poor nurture during infancy, Genetic, Attachment/Security, Unknown, Social/modeling behaviors, Stress during pregnancy,
	Treatment	Educational/behavioral programs, Professional services, Medication, Diet
	Social reactions to diagnosis	Stigma, Prejudice
Current Family context	Family unit	Single mother, Nuclear

	Parental roles at home	Mother does everything, To give child affection, Have to educate child, Mother has to prepare 3 different meals to accommodate preferences
	Child rearing practices	Strict, Easy-going, Fun, Playful, Educational, Lenient, Siblings help support each other, Mother and father have different approaches
	How were practices learned	Internet, Books, Family, Professionals
	Social network in Montreal	Only friends from same background, Limited, Non, Some relatives but they are not available to help, Other families with children with ASD
Parent Background	Physical setting	City, Village, On a small Island
	Living arrangements	Lots of extended and immediate family in the same house, Everyone knew each other on the island, Nuclear family, Raised by grandparents, Father works abroad in middle east
	Customs of care	Strict, Given freedom, Use of spanking as punishment, Use of grounding as punishment, Patient and calm, Frequently expressing love, Traditional parental roles (Mother at home and father working), Mother takes care of basic needs, Father takes care of needs outside of home and helps with their education, Belief in destiny and thinking positively, Parents very involved, Father works during the week but devotes all of his time on weekend to children, Mother was primary caregiver, Married early, Adolescents need to be supervised when forming relationships and courting, No use of technology, Importance of eating healthy
	Education	University, Study field of psychology/child development, Had a positive school experience, Do not include special needs, Worked in health field, Attended medical school, Study college in the health field
	Caregiver expectations	To finish school, To take care of the parents, Take care of parents' finances
Treatment Services	Type	Government/Private: SLP, OT, Individual behavior program, Social services, Parent support group, Children's ASD stimulation group
	Intensity	Over 10-hours; Under 3-hours, As needed
	Context of service	Center, Home, Daycare, Multiple sites as needed
	Professionals	Educators, Psycho-educator, Education specialist, Integration aid, Social workers, Behavior therapists, Psychologists, Occupational therapist, Speech and language pathologist
Perception of services	Positive	Superior than home country (illusion), Effective, satisfactory, Trustworthy, Felt relaxed that he son was

		there, Culturally responsive to family's needs, Parent felt emotional support from group service,
	Negative	Limited accessibility, Wait lists too long, Lack of stability/link with other services, Operate like a business, Insufficient duration/hours, Cases prioritized by severity and not need, High cost of private services, Inadequate services in French system, Program does not consider all of the parents' needs, Services are not really what they claim to be, Did not provide a report when parent requested, Times offered not flexible, Finds methodologies strange, You cannot wait for them to make the first move, Can exaggerate the child's problems, Insufficient communication and collaboration with professionals, Parents are not given enough time to determine how they wish to use subsidies, Services that can be used by subsidies are limited, Inadequate follow-up when service is complete, Do not attend to child's needs
Perception of Professionals	Positive	Open, Flexible, Experts, Caring, Warm, Similar backgrounds, Understanding, On the parents side, Intelligent, guide to accessing services, trust that they will make improvements, approachable, focused, helpful, supportive, be prepared for teaching children with special needs, Impressive, Comfortable, Good listener, Not understanding of language barriers, Gave a lot of troubling information about prognosis, Not as affectionate as parents
	Negative	Lack of communication, Do not do a sufficient job, Lack vocation, Not willing to do extra work unless paid, Pediatricians are not supportive to parents psycho-social needs,
Barriers	Family	Cost of therapy and services, sacrifice of time, conflicting cultural practices, Have to stop working, One parent needs to work more to compensate for the other not working, Lack of help from spouse, Separated, No family or friends to help support, Care for family back in home country, Marital problems, Father not supporting financially, conflicting systemic practices, Mother has to stop school to take care of child, Family needs to be separated because of child's special diet, Difficult to manage all appointments , Language barriers
	Child	Languages, conflicting cultural practices; experience discrimination by others;
	Accessing services	Wait lists, cost, resources,
Parental	Roles	Care-taker, Educator, Driver, Case-worker, Follow

involvement in services		instructions from professionals, Help child get through routine, Working/Independent mother, Be insistent on getting services, Watch instructors, Collaborate to establish goals, to carry out home routine so educators can watch and evaluate, Observe, Bring child to program and then pick them up, To work in parallel on improving his physical condition, Assist therapist during session
Parent professional relationships	Communication	Through communication books, In person, Formal meetings, Not much time to talk because there are too many children around, accessible, feel comfortable communicating needs, Trust, Infrequent communication, feel supported
Future expectations		To be autonomous/Independent, Play/interact with same age peers, to overcome delays, To no longer have label of autism, to find employment that he will be good at, will like, and will support his life, To no longer need all of the services, to go to primary school, Unsure of what the future holds, continues with biomedical treatments, Communicate and understand.