

**Autism and the Experiences of Immigrant and Culturally Diverse Families Accessing
Behavioral Interventions**

by

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Abstract

This study probed the experience of immigrant and culturally diverse families of children with autism accessing Applied Behavior Analysis (ABA) and other related behavior interventions. The study investigated whether these interventions met the socio-cultural needs of immigrant and culturally diverse families. The aim of the study was to contribute to a developing knowledge base on how these interventions can be delivered to optimize intervention outcomes for this specific group who have children affected by autism. Five families engaged in a semi-structured 45-minute interview over the telephone. Interview data were then analyzed in line with a grounded theory approach, comprising three analytical stages of open, axial, and selective coding. The study further utilized an eco-systemic framework to conceptualize the systemic issues and complexities that shape the experience of immigrant and culturally diverse children with autism.

Findings from the study revealed that ABA is an effective intervention for both immigrant and culturally diverse population and other families but that systemic barriers could affect successful engagement and outcomes for the immigrant and culturally diverse families. Such barriers to engagement include (a) delayed diagnosis, (b) age limitations on ABA program access and (c) lack of adequate language services. The study also revealed that factors such as parental education and level of awareness help mitigate the impact of these barriers. Recommendations have been made that would improve ABA program delivery. These recommendations outline a comprehensive service delivery approach to attenuate the multi-systemic barriers that affect successful engagement and intervention outcomes for immigrant families of children with autism.

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Chapter One – Introduction

Research Problem and Justification for the Research

Autism is a neuro-developmental disorder that is marked by deficiency in social communication, social interactions, and restricted and repetitive patterns of behavior, interests, or activities (DSM-V, 2013). Autism has an early onset with its symptoms evident in early childhood. The disorder is lifelong. The cause of the disorder remains uncertain, although findings from research have identified possible causes of autism that include genetic and environmental factors. Treatment approaches to autism focus on improving positive outcomes for the individual (Bertoglio & Hendren, 2009). Autism is estimated to have a prevalent rate of 1 in 59 children, according to a recent report by Centers for Control and Prevention (CDC, 2018).

Studies such as Bolton et al. (2014) and Dealberto (2011) indicate that the prevalence rate of autism is gradually increasing among immigrant and culturally diverse populations. Immigrant population is conceived, in this study, as individuals that were not born in Canada and had immigrated into Canada, regardless of how long they have lived in Canada. Culturally diverse population, as conceived in this study, refers to individuals from cultures that are different from main stream Canadian culture. Further description and rationale for the selected study group is included in the section describing the study “Methods.” Accordingly, there is a growing need for research on the experience of immigrant and culturally diverse families of children with autism. Findings from literature have drawn attention to the need for further study on issues peculiar to the experience of immigrant and culturally diverse families, including disparities in access to early diagnosis, and culturally appropriate interventions (Sritharan & Koola, 2019, Jo et al., 2015, Mandell et al., 2009). Research findings have indicated a low engagement rate in treatment programs, owing to reasons such as a lack of culturally appropriate interventions, distrust, absence of resources,

and language barriers (Mandell & Novak 2005; Ravindran & Myers, 2012; Munroe, Hammond, & Cole, 2016; Bernier, Mao, & Yen, 2010; Tek & Landa, 2012).

Taking into account the above reasons, this study examines the experience of immigrant and culturally diverse families of children with autism that are accessing Applied Behavioural Analysis (ABA) and other related behavior interventions. Specifically, the study queries the applicability and effectiveness of ABA and other related behavior interventions in meeting the psychosocial and cultural needs of this particular group.

More so, researchers such as O'Dell et al. (2016), have argued against adopting a cross-cultural perspective on autism. The authors make a case against the view that autism is a universal diagnostic/experiential truth that is similarly understood across cultural contexts. Such authors as Walters (2017) and Jack (2014), for example, claim that the construction of knowledge base over time has mirrored substantially the experience of White middle-class people to the exclusion of the peculiar experiences of culturally diverse individuals and families of people with autism, thus presenting autism, inadvertently as a “White middle-class condition.” Such conclusions depend largely on the reasoning that extant research on autism have, historically, focused essentially on White middle-class experiences at the expense of research on the experiences of culturally diverse populations who live with the condition. This gap in research justifies the need for further investigation and expansion of knowledge on how immigrant and culturally diverse populations construct and shape their experiences of autism, including diagnosis and treatment.

Further, the value of this research is clear against a backdrop of growing support for evidence-based practice (EBP) in social services delivery. ABA is gaining wide acceptance as one of the evidence-based treatment modalities for autism. Many provincial governments in Canada, including Ontario and Manitoba, have funded ABA programs because of the

evidence supporting its effectiveness. However, there is limited evidence for the effectiveness of ABA interventions among culturally diverse populations (Chang & Zaroff, 2017; Wang, Kang, Ramirez & Tarbox, 2019). To enable equitable access to treatment gains, it is necessary, therefore, to investigate how immigrant and culturally diverse families experience ABA interventions, including their perception of service outcomes.

Contribution to Social Work Practice and Social Policy

The current study is crucial to social work practice with the study's target population given that social workers are often carry out functions that include case planning and program evaluation for them. Miller, Cruz & Ala'i-Rosales (2019) call attention to a need to include values such as social justice and diversity in the discussion and evaluation of emerging autism behavioral interventions. The social work profession is at the frontline of advocacy for social justice and equitable access to resources and interventions as evident by the profession's enduring commitment to the values of social justice and service to humanity. Accordingly, there is a need for further investigation of how social workers can apply their professional training and values into making ABA and related behavior interventions more culturally appropriate and relevant for immigrant and culturally diverse families, thereby enabling them equitable access to appropriate treatment. The findings from this study contribute important insight into the ways that emerging evidence-based practices can be culturally adapted to serve a diverse population without undermining their values, worldviews, and belief system.

Objectives of the Study

The specific objectives of the study include:

- a) exploring the experience of immigrant/culturally diverse families of children with autism in Winnipeg that have accessed ABA interventions;

- b) identifying the ways through which current available ABA interventions can be culturally adapted to meet the needs of immigrant and culturally diverse families in Winnipeg; and
- c) expanding insight into practical ways to foster more effective working relationships between professionals and these families that are accessing ABA interventions.

Theoretical Framework

The study adopts the eco-systemic framework as a conceptual model for assessing the experience of the families accessing behavioral interventions. The theory, as advanced by Urie Bronfenbrenner (1979), proposes that environmental factors interact in multilayered and systemic ways to influence child development. This framework permits a comprehensive assessment of sociocultural factors within a family system that can determine outcomes of intervention services. The framework is further examined in the literature review section of this thesis.

Chapter Two – Literature Review

Autism in Immigrant Communities

There is a lack of consensus on whether there is any significant difference in autism spectrum disorder (ASD) prevalence across various ethnic groups. While some researchers contend that there are no significant differences in the rate of autism across various ethnic groups, socio-economic status or race, there are differences between the access to an early diagnosis for the child (Hall, Fruh, Zlomke & Swingle, 2017; Mandell & Novak, 2005). On the other hand, some studies have indicated significant differences in the prevalence rate of ASD among ethnic groups, race, and nationalities. Bolton et al. (2014) reported on a birth cohort study in Sweden between 1999 to 2003. The authors noted that the Somali population in Sweden were found to be four times as likely as the non-Somali population to develop ASD. A survey report from the Center for Disease Control and Prevention (CDC, 2014) revealed a lower estimate of ASD prevalence rate among Hispanic children (10.8 per 1000) compared to non-Hispanic children (15.8 per 1000). Similarly, a study by Becerra et al. (2014) reported that ASD rate is 36% higher for children of immigrant mothers compared to their counterparts. Another study by Dealberto (2011) noted that immigrant mothers of Asian origin were 25% more likely to have a child with autism compared to non-immigrant mothers.

Bolton et al. (2014) reported that immigrants from Sub-Saharan Africa were 75% more likely to be diagnosed with autism. Bolton et al. (2014) had compared African immigrants in Ireland with their Irish counterparts and a smaller group of other ethnicities. The authors observed that the children from Sub-Saharan Africa diagnosed with autism showed more severe symptoms of autism, including severe cognitive delays. They also showed a higher heritability rate (39% compared to 26.3% for their Irish cohorts) of having a family history of autism traceable to first-degree relatives. The authors noted that Sub-

Saharan African children with higher birth order had a higher risk of autism based on the findings from the study. The authors cautioned that some other factors could account for the higher autism risk found in Sub-Saharan children in the study. For instance, the authors noted that immigrant children with severe autism symptoms are more likely to present for diagnosis compared to those with mild symptoms, given that immigrant parents tend to be reluctant to seek autism services earlier due to such factors like ignorance and shame that are often attributed to disabilities in some ethnic communities. The authors also questioned whether perhaps more children with severe autism symptoms from Sub-Saharan Africa participated in the study compared to their Irish counterparts.

Hess, Morrier and Heflin (2008) completed a study with 185 teachers who work with children with autism. The authors found that over 50% of children receiving interventions to address issues because of autism were Caucasians. A third of the remaining population were African Americans and a smaller percentage of the study's population was comprised of Asians, Hispanics, or mixed races. In another study by Thomas, Ellis, McLaurin, Daniels, and Morrissey (2007), the authors found that multicultural and immigrant groups underutilized autism interventions compared to mainstream population. In this study, the authors had interviewed 383 families from North Carolina who were accessing autism related services.

Findings from the study by Thomas et.al., revealed that minority families utilized case management services less than half of the time and utilized the services of a psychologist less than quarter of the time, when compared to mainstream families. A noteworthy point raised in the study is that immigrant families of children with autism experience significant barriers to accessing appropriate services. These challenges are in addition to many other challenges faced by the immigrant population: language barriers, unemployment, and inadequate social supports. These variables are crucial and deserve consideration in any study on the experiences of immigrant families of children with autism.

Several studies have indicated that immigrant and culturally diverse children tend to be diagnosed later when compared to their Caucasian counterparts (Sritharan & Koola, 2019, Daniels & Mandell, 2013). Mandell et al. (2002) investigated a diverse ethnic population of children to uncover the average age at diagnosis. The children in the study were comprised of African American (59.6%), Caucasian (29.1%), Latino (8.1%), and other races (3.2%). The authors found that Caucasian children received an autism diagnosis at 6.3 years of age on average, whereas African American children received a diagnosis at age 7.9 years and Latino children at 8.8 years. Some possible reasons for the delay in diagnosis for immigrant children have been attributed to a lack of awareness of any available services, a reluctance to seek treatment due to stigma and a language barrier (Zuckerman et al., 2014). Important to note is that research findings on autism have indicated that an early diagnosis is a significant determiner of positive treatment outcomes (Vietze & Lax, 2018, Turner & Stone, 2007). It was found that in some cases, immigrant children are unable to fully benefit from the gains of treatment due to a delayed diagnosis.

Autism Interventions

To provide a further understanding to the barriers for successful treatment outcomes for the children of immigrant and culturally diverse parents, it is beneficial to have a short discussion on the availability of autism interventions. These interventions range from evidence-based treatment modalities to cultural and spiritual approaches to treatment. Early diagnosis, high intelligence quotient (IQ), and language ability, as well as other factors, have been correlated to positive treatment outcomes, (Bertoglio & Hendren, 2009). Bertoglio and Hendren (2009) stated that treatment may not lead to the remission of core autism features, but effective autism treatment may help gain substantial adaptive skills, especially when various treatment modalities are used in collaboration with one another.

Pharmacological interventions are mostly used to target specific associated features of autism such as aggression and self-injurious behaviors. Such interventions include the use of antipsychotic drugs such as Risperidone, Abilify, Seroquel, and Serotonin Re-uptake Inhibitors (SSRI) like Fluoxetine, to alleviate symptoms such as compulsive behaviors, rigidity, and anxiety. These drugs, however, can present with side effects such as weight gain, sedation, irritability, aggression, and insomnia (Bertoglio & Hendren, 2009, Hollander, 2005).

Complementary and Alternative Medical (CAM) treatment is a biomedical approach that has also gained a level of acceptance among families seeking autism interventions. CAM interventions target biological functions. An example of a CAM intervention is the use of hyperbaric oxygen therapy and omega-3 fatty acid to treat inflammatory process that children with autism seem to develop. (Amminger et al., 2007). This inflammatory process, also referred to as “leaky gut” implies that the intestinal tracts of children with autism are permeable and allow toxins and bacteria to enter the blood stream thereby affecting brain functions (Bertoglio & Hendren, 2009). Proponents of this treatment approach contend that diets such as omega-3 fatty acid, dairy products and wheat can help promote the growth of a healthy gut to treat this condition. Bertoglio and Hendren (2009) noted that although parents have reported experiencing some benefits from CAM interventions and the number of users of CAM continues to grow, evidence for effectiveness of this treatment model is limited and at best considered anecdotal.

Behavioral interventions have received considerable acceptance as a viable intervention model within the field of autism research. There are various forms of interventions that target behaviors such as ABA, Treatment and Education of Autistic and Communication Handicapped Children (TEACH), occupational therapy, speech therapy and language therapy, etc. Occupational therapy focuses on integrating a child’s sensory needs

through the learning of skills that allow for sensory input that can enhance the child's ability to self-regulate independently and appropriately (Bertoglio & Hendren, 2009). Speech and language therapy target communication issues to help children with autism communicate in useful and functional ways. Interventions provided by speech and language therapists include improving spoken language, nonverbal skills, and alternative communication with pictures, sign language, and electronic devices (Battol & Ijaz, 2015).

Of note, this study will focus more on ABA interventions, considering that ABA is currently gaining wider acceptance in the autism community as an evidence-based practice. In addition, ABA is the primary form of early intervention that is funded by several Canadian provincial government (Dudley & Emery, 2014).

ABA comprises a variety of intervention models such as Discreet Trial Training (Lovaas, 1987), Incidental Teaching (Hart & Risley, 1975), Picture Exchange Communication System, (Frost, 2002), Pivotal Response, (Koegel & Koegel, 2006), Verbal Behavior (Sundberg, 2008), and Early Intensive Behavior Intervention (Lovaas, 1987, Liao, Dillenburger & Buchanan, 2018). The goal of ABA is to teach socially adaptive skills and lessen maladaptive behaviors. ABA is considered scientific because it uses scientific controlled guidelines to analyse a learned behavior and to justify that the learned behavior is a direct response to a consequence or stimulus that was introduced during the behavior conditioning process (Cooper, Herod & Heward, 2007).

Lovaas' study (1987), contributed immensely to the development of ABA as an intervention in autism. The study directly compared two groups of children; one group that received intensive behavior interventions and the other group that received non-intensive interventions. The author found that 47% of the children that received intensive behavior interventions were indistinguishable from their peers at follow-up and had acquired a mean

average of 30 intelligence quotient (IQ) points when compared to the control group who received non-intensive behavior interventions. Following Lovaas' study, several other researchers continued to build on his findings by studying the effectiveness of ABA as an intervention for autism. Their findings highlighted similar results as Lovaas (Eldevik, Elkeseth, Smith, Jahr & Smith, 2006).

ABA Effectiveness and Validity for Multicultural Groups

As evidence in support of ABA interventions continue to grow, there remains unanswered questions about the appropriateness of its application to cross-cultural situations. Researchers have questioned whether ABA interventions would produce similar effective outcomes when used with diverse cultural groups. This question raises the issues of social and cultural validity of ABA interventions. Social validity is a construct coined by Wolf (1978) to suggest that the consumer should evaluate the goals and procedures of an intervention. Quintana, Troyano and Taylor (2001) advanced this concept to describe the notion of cultural validity; where cultural validity refers to an authentic cultural representation of research that questions how constructs are operationalized, participants are recruited, hypotheses are formulated, study procedures are adapted, responses are analyzed and results are interpreted for particular cultural groups.

With reference to the authors' definition of cultural validity, it is arguable that little or no studies have successfully proven ABA interventions as being effective in cross-cultural situations (Li & Kimble, 2016, Chang & Zaroff, 2017). Studies that have investigated the cultural validity of ABA interventions have indicated mixed results. Chang and Zaroff (2017), for example, uncovered that, although ABA interventions are arguably the most utilized behavioral interventions in China, children with autism in China and Hong Kong accessing ABA interventions scarcely exhibit significant improvements in behavior. Of note, the authors attributed this poor outcome of treatment to the lack of adequate staff training.

Besides the lack of staff training, a few other reasons have been current to explain the disparity in ABA treatment outcomes for culturally diverse populations. West et al. (2016) postulated that the lack of adequate representation of culturally diverse groups in the research on autism and evidence-based practice (EBP) could account for the difference in the outcomes of interventions with culturally diverse groups. The authors reviewed the extant literature on EBP research on autism. Referencing the findings of Pierce et al. (2014), the authors noted that 72% of the articles published in respected autism journals between 2000 and 2010, did not report on the race, ethnicity, or nationality (REN) of participants in their studies. West et al. (2016) identified six EBP studies that did not adequately report on the REN of participants. In particular, they noted that four of these studies were mostly on well established behavioral interventions modelled after ABA principles, including discrete trial teaching (DTT), extinction and picture exchange communication system.

The authors, West et al. (2016), further noted that white British, Polish, Tasmanian and New Zealanders children represented 19.6% of the total of 2489 participants in the 408 EBP studies examined. They further elaborated that these nationalities accounted for 63% of the participants in 73 of the EBP studies that had adequately reported REN. The participants that were multiracial in these studies only accounted for 6.4% of the overall participants of the 408 EBP studies and 20.6% of the participants in the 73 EBP studies reporting on the REN of participants. West et al. (2016) concluded that a limited number of studies on EBP in autism research adequately report the REN of their participants. The authors further concluded that culturally diverse groups have been largely under-represented in EBP studies. The authors contend that an underrepresentation of culturally diverse groups in research on EBP raises questions about the efficacy of these interventions for the underrepresented groups which include culturally diverse and immigrant families. These findings are consistent with findings from studies by Wong et al. (2014) and Pierce et al. (2014).

Wang et al. (2012) commented that behavior interventions should provide an in-depth look at value differences across cultures. For instance, some behavioral supports may be informed by values towards assertiveness and directedness versus maintenance of harmony. Some behavioral interventions that focused on meaningful life outcomes may be more oriented towards individualism versus the promotion of the family unit and collectivism. Perepa (2014) interviewed parents of children with autism and found that White, British families and South Asian families placed more importance on teaching their children to follow rules and to respect personal space, whereas African-Caribbean, and Somali families placed more emphasis on teaching their children to maintain eye-contact.

These differences have real consequences for multicultural families of children with autism as they are receiving behavioral interventions that have been predominantly informed by white values and ways of knowing. Families may struggle with implementing the recommendations that service providers make regarding home-based behavior interventions given these noted differences in values. Some parents could have language barriers and may struggle with implementing these recommended activities in English. More so, terminologies and values in behavior interventions may mean different things in the heritage language of caregivers and may generally not be useful for the family as a system.

Other researchers have argued that ABA can be culturally adapted to meet the needs of culturally diverse groups. Leaf et al., (2016) argued that ABA is scientific and that science by its nature, is progressive. The authors put forth that the progressive nature of science allows for flexibility. This type of flexibility makes it possible for ABA to be culturally adaptable without deviating from the core tenets of the approach. To test the above claim, some studies investigated the effects of accommodating core aspects of a culture, such as language and family values in the planning and delivering of ABA interventions. In the following paragraph will look at these studies.

Lang et al. (2011) delivered a version of Discrete Trial Training (DTT) to a child in English and in the child's native language which was Spanish. The authors observed more correct responses and a reduction in challenging behaviors when the intervention was delivered in the child's native language. Spector and Charlop (2018) also compared intervention outcomes for four children with autism between ages 8-12 years. The ABA therapist gave play instructions in English and then in the child's native language. The authors observed a significant reduction in challenging behaviors when the therapist delivered instructions in the native language rather than in English.

Cultural Considerations for Improving ABA Delivery

Considering the outcomes from the above studies, evidence exist that suggests that services could be improved if aspects of culture such as language is integrated into the ABA interventions. It is, however, almost impossible to deliver ABA interventions in multiple languages as it would require multi-lingual therapists, something that is unrealistic to expect. In cases where a therapist speaks the child's native language, translating instructions to the native language could also be challenging.

Walker Jones and Hoerger (2009) researched the effectiveness of a culturally adapted ABA intervention. The authors delivered Intensive Behavioral Intervention (IBI), which is an ABA intervention, in the Welsh language. This was a single case study of a six-year-old child. They concluded that some significant improvements were observed in areas such as verbal speech, vocalization, and non-verbal communication skills. The authors did report experiencing significant challenges when translating the technical words found in ABA from English to Welsh. In some cases, the translated words were open to having different meanings from the English word. A critique of the study is that the findings are limited as it involved only one participant. More so, the study did not utilize a control group to compare

the effectiveness of the culturally adapted ABA intervention with the same intervention delivered in the English language.

As noted earlier, although it may be difficult to deliver ABA interventions to a linguistically diverse group of participants given their different native languages, Li and Kimble (2015) suggested some cultural considerations that could be integrated into the planning and delivery of ABA programs to make the intervention culturally appropriate and responsive. The authors noted that the planning of a culturally appropriate intervention should consider factors such as the language dominance and proficiency of caregivers, the social economic status of the family, and the parents' level of acculturation vis-à-vis the child's acculturation level. Parents' level of acculturation, for example, may be different from the child's acculturation level in the sense that an immigrant child, because of their engagement in school, may have acquired the relevant socio-cultural competencies to help them better adapt to their new environment, while the child's parents may have yet to successfully acquire these socio-cultural abilities, partly due to language barriers. This difference in acculturation level may contribute to parents' being unable to fully support their child in engaging in the ABA intervention process. The authors further suggest that service planning should consider the nature of relationships that exist between the families and any collateral systems such as schools, hospitals, therapists, and other service providers.

Miller, Cruz & Ala'i-Rosales (2019) uncovered in their study that planning a culturally appropriate intervention requires that the goals and procedures of the intervention align with the cultural values and worldviews of the families that the intervention is intended for. The authors suggest there is a need for self-reflective practices which would help therapists identify and address their cultural biases. According to the authors, self-reflection enables a comprehensive intake process, allowing the therapist to pose open-ended questions in ways that elicit responses that give a fuller, more in-depth understanding of the values and

aspects of culture that are salient for the families. The authors noted that this type of open dialogue and rapport building with families would engender a more meaningful engagement in the intervention process.

Ijalba (2015) noted that effective planning of interventions for culturally diverse families need to incorporate the views and supports of the extended family as well. The author explained that given the collective orientation of most culturally diverse families, it is important to remember that relatives have a significant influence on the decisions parents make regarding the types of interventions accessed for their children. Another researcher, Kitzhaber (2012), identified key factors that contribute to successful engagement of immigrant families in interventions designed to address problematic characteristics of children affected by autism. These key factors are family perception of gender roles, parental responsibilities, child development, and child rearing beliefs. The author notes for example, that knowledge of gender roles is important as such an understanding would help service providers know how to engage household members based on their gendered roles within their family's cultural beliefs and practices. Gender roles relate to how tasks are assigned within the family, including decision making on important matters, responsibility for caregiving, attending appointments and engaging with service providers. The author mentioned that in most culturally diverse families, the above tasks are divided along gendered lines and signify power distribution among household members. Service providers need to be aware of these dynamics so as to successfully engage household members in the intervention process.

Theoretical Frameworks

The above paragraphs speak to the need for a culturally appropriate intervention plan to obtain positive outcomes for multicultural and immigrant groups. This type of service delivery model is even more complete when it is developed with an appropriate theoretical framework. This study will adopt an eco-systemic framework to understand the needs,

strengths and challenges of immigrant families that are accessing autism interventions. By doing so, it is anticipated that the study will identify factors that contribute to successful intervention planning, delivery, engagement, and outcomes for immigrant and culturally diverse families of children with autism.

The eco-systemic model advances the proposition by Bronfenbrenner (1979) that human development occurs within progressively complex reciprocal interaction processes (proximal process) between the developing child, caregivers, and their environment (Bronfenbrenner, 1979, Bronfenbrenner & Morris, 2006, Ijalba, 2015). This proximal process is mediated by varying characteristics of the developing person; the immediate and remote environmental contexts; and the time periods of interactions (Ijalba, 2015). These four key constructs of process, person, contexts, and time (PPCT), according to Ijalba (2015), have utility for understanding the experience of immigrant and culturally diverse parents of children with autism and, therefore, developing appropriate interventions for them.

More so, environment, in the eco-systemic model, is conceptualized as a network of systems constantly interacting to shape the development of a person in their environments (Guckin & Minton, 2014, Bronfenbrenner, 1979, Guy-Evans, 2020). The Micro-system is the child's immediate environment where the child has direct contact with people and things in their environment, including family members, school personnel, and peers. This social space is characterized by dyadic relations because it involves a bi-directional nature of interaction, where a child has the capacity to influence the behavior of others in their environment. Likewise, a child is also affected by the actions of others in the child's micro-environment (Guckin & Minton, 2014, Bronfenbrenner, 1979, Guy-Evans, 2020).

The meso-system refers to the interactions that happen among the various networks of systems in the child's microsystem (Guckin & Minton, 2014, Bronfenbrenner, 1979, Guy-

Evans, 2020). The nature of interaction between a child's parent and a behavior specialist, for example, may affect the outcome of the ABA intervention. Where caregivers and service providers, for instance, do not get along, the level of parental engagement needed to yield positive intervention outcome for the child may be affected.

The exo-system comprises systems that are external to the child's immediate environment but indirectly influence the child's development (Guckin & Minton, 2014, Brofenbrenner, 1979, Guy-Evans, 2020). Such systems like parents' workplaces may indirectly affect a child's experience of ABA intervention. For example, where an employer is inflexible with work schedules, a parent may have difficulty attending an ABA session with their child, thus affecting the parents' ability to acquire necessary skills to help care for their child.

The macro-system refers to the existing cultural elements in the society that the child is raised (Guckin & Minton, 2014, Brofenbrenner, 1979, Guy-Evans, 2020). These elements such as beliefs, attitudes and values shape how the child is raised and they influence the child's development. For example, the kind of attitude that society has towards immigrants or certain ethnic groups and race may affect the quality of service delivery to a child from such cultural and ethnic groups.

The chrono-system refers to the changes in the child's environment across a life span (Guckin & Minton, 2014, Brofenbrenner, 1979, Guy-Evans, 2020). These changes can include normative changes marked by milestone developments such as school entry and exit. It could also be marked by non-normative changes such as parental divorce, or a pandemic. A non-normative change such as relocation to another city, for example, may affect a child's access to existing ABA services in their current environment.

Although the ecosystemic model is useful for completing a comprehensive assessment of strengths and needs, this model nonetheless, has attracted some criticism. Christensen (2016) contended that the model appears to discount the significance of individuality and entrepreneurship. Christensen argues that the model places greater attention on the influence of environmental factors and systems on child development than on the resiliency of the child or the efficacy of the child's inherent abilities and self-will (Darling, 2007, Siporin, 1980).

Notwithstanding the above criticism, the ecosystemic model has utility for the present study. It enables a richer understanding of how the resources in community can be successfully deployed to meet the unique needs of immigrant and culturally diverse families of autistic children. This concept is similar to the ideas advanced by Kitzhaber (2012). The author discusses the eco-systemic framework in relation to the notion of "goodness-of-fit." This concept emphasizes the need for a parity between available resources and the psycho-social context in which families exist. The concept further supposes that a supportive and safe environment enables a child to positively develop and realize their full potential (Ohmer, 2010). This perspective offers more usefulness for planning autism interventions for immigrant families because it reinforces the importance of developing a service plan and relationship with families to integrate their values, beliefs, and support systems.

Research Questions

Developed from the available information from the review of literature in this research area, the research questions underlying this study are:

- a. Is ABA culturally appropriate for immigrant and culturally diverse families of children with autism?

- b. What aspects of ABA intervention goals, process and outcomes do immigrant and culturally diverse families of children with autism consider important and useful to meeting their needs?
- c. What demographic and cultural features influence positive engagement in the ABA intervention process, and positive outcomes for immigrant and culturally diverse families of children with autism?
- d. What challenges and barriers do immigrant and culturally diverse parents of children with autism in Winnipeg experience while working with service providers of ABA and other related behavior interventions in home and community settings?
- e. What kinds of supports and resources can be useful to mitigate the challenges and barriers that immigrant and culturally diverse families of children with autism in Winnipeg experience as they access ABA interventions?
- f. How can the findings from research be integrated into developing a culturally effective framework for delivering ABA interventions to immigrant and culturally diverse families of children with autism?

Summary

This literature review focused on evidence-based findings on the effectiveness and appropriateness of using ABA interventions with immigrant and culturally diverse families. The review examined evidence supporting the claim that ABA is adaptable to cross-cultural contexts, where families regardless of their cultural backgrounds, can benefit from ABA interventions.

The review also examined arguments questioning the effectiveness of the use of ABA interventions in cross cultural situations, due to barriers resulting from differences in cultural worldviews, beliefs, and values. Overall, there was more evidence in support of the use ABA in cross cultural situations. Findings revealed that an adaptation process that carefully

considers culturally differences and systematically integrates cultural values and practices in the planning of ABA interventions would better serve the needs of immigrant and culturally diverse families of children with autism accessing ABA interventions.

Chapter Three – Methods/Methodology

Research Design

This study utilized a qualitative research design to investigate the experiences of immigrant and culturally diverse families of children with autism accessing ABA and other related behavioral interventions. In line with qualitative research, this study adopted grounded theory methodology for data analysis. Grounded theory is oriented towards developing a theory to explain a process, action or causes of an event/phenomenon within the context of people's experience of a phenomenon (Creswell & Poth, 2018). Grounded theory was advanced in this research to help explain the processes, along with individual and systemic elements that shape service delivery and outcomes for the participating families.

The application of grounded theory to the phenomenon under study was guided by an eco-systemic framework. Grounded theory was used to analyze and interpret data that describe how features such as language, values and belief systems affect interactions between families and their collateral systems as well as the implications of these interactions on effectiveness of service delivery and outcomes.

The study followed guidelines laid out by the University of Manitoba, Research Ethics Board (REB). The study received approval (Appendix 7) to conduct the research with the designated population and to abide by standards of confidentiality and informed consent. In line with these standards, the informed consent (Appendix 4) was completed with participants. Participants were completely informed about the nature and scope of their involvement in the study, including the risk and benefits. Participants were fully advised that participation in the study is voluntary and could be terminated at any point in time during the research. Data was securely protected in line with confidentiality guidelines, where data was stored in the researcher's workspace, which is only accessible to the researcher and kept in a locked box. The researcher and their faculty advisor signed an Oath of Confidentiality as

required by the REB. In keeping with the Oath of Confidentiality, information about participants was only discussed between the researcher and their faculty advisor.

Sampling

The study utilized a purposive sampling design. This type of sampling design, noted by Padgett (2017), refers to “a deliberate process of selecting respondents based on their ability to provide needed information” (Padgett, 2017, p.67). The sampling design is purposive because the study investigated the experience of immigrant and culturally diverse families of children with autism and as such, participants needed to be recruited from this specific population.

In addition to the above, the study utilized a snowball sampling design. As noted by Padgett (2017), snowballing is used in situations where access to prospective participants could be difficult due to factors that may include distrust, fear, or reluctance to speak about private matters. The immigrant population is sometimes difficult to access or penetrate as they may be reluctant to discuss family issues with an outsider. Accordingly, the study engaged the snowball technique to connect with this population, through asking recruited participants to help invite other prospective participants to the study. This technique is believed to help lessen the fears that prospective participants may have regarding the research since invitation to the study was done by familiar individuals who share similar cultural beliefs and experiences with the prospective participants.

Recruitments

The study recruited five families. The parents that were recruited for this study were all immigrants from culturally diverse backgrounds. The parents all have a child that had been formally diagnosed with autism. One family had a child that is over the age of 18 years while the other parents' children were of middle and adolescent ages. All the parents

recruited in the study have resided in Winnipeg for over five years. Two families were Nigerians, one family was Caribbean, one family was Filipino, and another family was Rwandan/Burundian. Most of the parents recruited in this study work within the social service field except for one parent that runs a private business. They were all university educated with degrees in social sciences and business. Three parents had social work degrees, one parent had a degree from the medical field, one parent had a degree in computer science, and one had a degree in business. All the parents spoke English fluently. Interpreter services were not warranted as language was not a barrier to reaching the participants.

Data collection was done primarily through a semi-structured interview, often lasting between 45 minutes, averagely. The strategy for the recruitment was in line with purposive and snowballing techniques earlier mentioned. In line with purposive sampling, recruitments were targeted towards immigrant and culturally diverse families that have children with a formal diagnosis of an autism condition and had accessed ABA or partially related behavior interventions, that include school-based behavior management programs or behavior modification services provided by private tutors. An environmental scan of relevant community programs that may be connected to the targeted participant pool was conducted through online research and conversations with community members who would have knowledge of the relevant programs that could be contacted. This process led to the creation of a resource information sheet that comprised some of the relevant community resources identified. Please see Appendix 7 for a copy of the created resource information.

Some of the community organizations contacted for recruitment purposes included St. Amant Center and its ABA program, African Communities of Manitoba Inc. (ACOMI), Newcomers Employment and Education Development Services Inc. (N.E.E.D.S.), cultural centers for different ethnicities, including Philippine Canadian Center of Manitoba (PCCN). Counselling resources for immigrant such as Aurora Family Therapy and Family Dynamics,

as well as places of worships where immigrant families often attend were contacted.

Resource teachers and school administrators were approached for assistance with recruitment.

The table below indicates the various community resources that were contacted for assistance with recruitment into the study.

Table 1: *Community Resources Contacted for the Study*

African Communities of Manitoba Inc. (ACOMI) 101-421 Kennedy Street Winnipeg, Manitoba, R3B 2N2 204-221-6696	St. Amant 440 Chemin River Road Winnipeg Manitoba R2M 3Z9 204-256-4301
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<p>Aurora Family Therapy</p> <p>491 Portage Avenue</p> <p>5th Floor</p> <p>Winnipeg, Manitoba</p> <p>R3B 2E4</p> <p>204-786-9251</p>	<p>Manitoba Possible</p> <p>825 Sherbrook Street</p> <p>Winnipeg, Manitoba</p> <p>R3A 1M5</p> <p>204-975-3010</p>
<p>Immigrant and Refugee Community Organization of Manitoba (IRCOM)</p> <p>95 Ellen Street</p> <p>Winnipeg, Manitoba</p> <p>R3A 1S8</p> <p>204-943-8765</p>	<p>Elmwood Community Resource Center</p> <p>545 Watt Street</p> <p>Winnipeg, Manitoba</p> <p>R2K 2S2</p> <p>204-982-1720</p>
<p>Family Dynamics</p> <p>393 Portage Avenue</p> <p>Winnipeg, Manitoba</p> <p>R3B 3H6</p> <p>204-947-1401</p>	<p>Emmanuel Fellowship</p> <p>828 Silverstone Avenue</p> <p>Winnipeg, Manitoba</p> <p>204-261-0172</p>

<p>New Directions</p> <p>500-717 Portage Avenue</p> <p>Winnipeg, Manitoba</p> <p>R3G 0M8</p> <p>204-786-7051</p>	<p>Newcomers Employment & Education Development Services Inc. (N.E.E.D.S.)</p> <p>251a Notre Dame</p> <p>Winnipeg, Manitoba</p> <p>R3B 1N8</p> <p>204-940-1260</p>
<p>Philippine Canadian Center of Manitoba (PCCN)</p> <p>737 Keewatin Street</p> <p>Winnipeg, Manitoba</p> <p>R2X 3B9</p> <p>204-775-4928</p>	

Recruitment letters (Appendix 2) were provided to all potential referral sources. The recruitment letter covered details of the study including the study’s objectives, data collection strategy, the required participant pool as well as risks and benefits of participation in the study to the families. A recruitment poster (Appendix 1) consisting of summary details about the study and contact information of the investigator was included with the letters. There was some positive interest from the recruitment letters and representatives from various

organizations followed up to inquire further about the study and to ask how they could be helpful. The agencies were requested to help disseminate information about the study to relevant participants by posting the study poster on their agency website or sending emails about the study to parents that may fit the eligibility criteria for the study.

The snowball technique proved more successful with recruitment compared to the initial strategy of contacting relevant agencies. With snowballing, potential participants were invited to the study by familiar people who share similar experiences and cultural backgrounds with the potential participants. To avoid undue influence or coercion by a third party, invited participants were left to make an independent decision about their participation in the study after a brief conversation with the investigator where they were able to ask questions about the study, allowing them to make a more informed decision about being involved in the study. The referrals of eight families were received in total, but three referrals did not participate. Two of the three referrals did not participate because they felt that their family did not engage in any type of ABA or other related behavior interventions and thus would not be able to contribute meaningfully to the study. The other referral, although willing to engage, could not participate due to being extremely busy with employment and family demands. The right to decline by referred potential participants was fully respected and there were no penalties for refusing to participate in the study. Out of the five families that were successfully enrolled in the study, four of the families were referred through the snowball technique of invitation by co-participants and friends. The other referral came through the assistance of one of the community and religious centers that the investigator had contacted.

A reason for the success of the snowball technique over the other strategies lies in the direct and purposive flow of information to the potential participants. Although a few agencies that offered their assistance with recruitment did post the study poster on their websites, it was likely that the potential participants did not take notice of the advertisement

or may not have had time to read through the poster information. More so, the Covid-19 pandemic had a major influence on this process, given that most program buildings were closed, and in-person services were suspended. As such, agencies could only disseminate information about the study by posting the recruitment poster on online forums, which may not necessarily be accessible to some immigrant families.

In accordance with ethics guidelines, participants that elected to engage in the study completed an informed consent form (see appendix 4). Due to Covid-19 restrictions, the process of completing the informed consent was conducted virtually. The consent form was sent to participants via their emails prior to the interview and participants were encouraged to read the forms before the telephone discussion with the investigator. During the telephone conversation, the investigator reviewed the consent form with the participants and answered their questions. The participants were asked to sign the consent form and send it to the investigator either through email or post mail. One participant sent the signed consent form via post mail whereas the others scanned and sent the signed consent form via email.

The table below presents an overview of the demographic information of the participants recruited in the study to further understand the backgrounds of the participants in the study.

Table 2: Demographics Table

Demographics	Number	Percentage
Recruitment Sources		
Worship centers	#1	20%
Referral by participants	#1	20%
	#3	60%

Referral by community members		
Education Level Post secondary level	#5	100%
Length of Stay in Canada 0-5 years	#0	
5-10 years	#2	40%
10 years and above	#3	60%
Household Type Single-head household	#1	20%
Dual-head household	#4	80%
Ethnicity African	#4	80%
Asian	#1	20%

Interview

Interviews were carried out over the telephone. A video meeting was not offered because participants did not express a need for this interview platform. The interview was recorded, and notes were taken during the interview. The recorded interviews were saved on USB stick. The USB stick and interview notes were stored in a locked box in the investigator's workspace and the investigator was the only person who had access to the key.

Commencing the interview, however, posed some difficulties due to the nature of the challenges the families face, including caregiving duties, and family commitments. As such, interview schedules were informally set as tentative schedules and, in some cases, interviews needed to be rescheduled as cancellations occurred. These scheduling difficulties underline the reality of immigrant families of children with autism. They must grapple daily with various caregiving challenges that make their routines unpredictable. However, these difficulties highlight the resilience and strengths of these caregivers in their ability to effectively navigate unpredictable situations and still manage to establish stable routines for their children, considering how important stability and predictability are to children living with autism.

The interviews lasted for approximately 45 minutes, averagely. Semi-structured questions (Appendix 9) were asked during the interview to elicit information from parents on their experience, including their early awareness of autism, the process of obtaining a diagnosis, and then trying to access services. These questions were informed by findings from literature on the barriers experienced by immigrant families accessing ABA interventions. The questions were also formulated to garner information related to the research objectives of this study. Participants were asked about their impressions about interventions they accessed, including ABA and other related behavior interventions. The investigator also queried for participants' impressions on service inadequacies, barriers to service accessibility, and impact of value differences in their engagement with service providers.

Language was not a barrier in the interview process. Participants spoke the English language fluently. Since both parents were not mandated to participate, there were cases where a parent decided not to participate but the other parent did participate in the interview. The decision of a parent choosing not to participate seemed to be related to scheduling

difficulties and comfort level. In cases where both parents participated, the interview was conducted with both at the same time. Both took turns answering the questions. No major disagreement was observed between parents on any question during the interview. However, it was observed that one parent would supply more information to a question in instances where they felt the other did not fully elaborate. Participants in the study were forthcoming and open with sharing their experiences. They did not express discomfort when responding to any of the questions posed. After each interview, the participants were debriefed to assess for any risk or traumatic impact that may have resulted from the interview process. No participant expressed any concern or emotional distress from the interview. Furthermore, information about relevant community resources were shared with the participants should they need to connect with support services following the interview. The investigator's contact information was also given should participants think of anything else they wanted share.

Data Analysis

As mentioned earlier, data was analyzed in line with the grounded-theory approach. One utility of this approach is that it allows the investigator to formulate a theory to explain nuances in service experience and outcomes. In line with the grounded theory approach, data collection and analysis occurred simultaneously and was ongoing. Data obtained during an interview with one participant was analyzed prior to the interview with the next participant. Therefore, questions arising from the analysis of one interview, influenced the nature of questions posed in the interview with the next participant.

Only parents that have not accessed any form of behavior interventions were excluded from the study. Two referrals disclosed they had not accessed any form of behavior interventions and, therefore, were excluded from the study. Referrals met inclusion criteria of the study if they have accessed ABA or other related behavior interventions regardless of the time when that the intervention was accessed.

Interview data was transcribed. The transcript was sent to the participants for their review prior to analysis. None of the participants expressed any issue with the transcripts and so, the analysis of the data was carried out. At the stage of analysis, participants' information was coded for identification purposes. Random letters and numbers were assigned to each participant and a sheet was developed that contained a link between the generated identity codes and the actual participants' identifying information. The interview data was saved on a USB stick. The USB stick along with hard copies of interview notes were securely stored in a locked box in the investigator's workspace.

In line with a grounded theory approach, data was examined at three levels of analysis, including open, axial, and selective coding. At the open coding stage, each interview was analyzed separately. General categories were generated from each interview by identifying emerging themes from the data. A core category depicting the focus of the research was then identified while the other themes were developed into sub-categories, based on meanings conveyed by the emerging themes. The core category pertains to the barriers immigrant and culturally diverse families of children with autism encounter. This theme became the central focus of the analysis at the open coding stage, given that all participants interviewed shared they had experienced barriers when accessing ABA or other related behavioral interventions. Subcategories of themes that were generated during this stage include a) a lack of experience and familiarity with autism, b) a lack of viable alternatives to service access, c) differences in worldviews affecting relationships with service providers, d) denial, and e) a lack of trust in ABA intervention. This stage of analysis only coded themes as they emerged but did not analyze patterns or relationships among the themes.

During the axial coding stage, the identified categories from each interview was further grouped into clusters of categories that are based on relationships among the sub-categories. Data was analyzed in two phases. In the first phase, data was analyzed based on how the relationships among the themes relate to the research questions guiding this study. In the second phase, the relationships among the themes were analyzed based on how the themes describe the participants' experience of the phenomenon.

Constant comparisons were made among the themes generated in each interview. Common themes from each interview were then grouped together as integrated data to be further analyzed.

At the selective coding stage, a conceptual framework was developed based on the relationships identified among the emerging categories. This framework explained the phenomenon under study, the context of the phenomenon, challenges and needs identified by participants with lived experience of the phenomenon, as well as the coping strategies, outcomes, and recommendations. At this stage, the identified categories were further streamlined into micro and macro level categories in line with the eco-systemic framework.

Further, participants' demographic information was collected for analysis purposes. These demographics included ethnicity, race, nationality, household type (i.e., single-head, or dual-head), education level, occupation, and length of stay in Canada. This information was used to determine if there were significant differences among the responses of participants from different demographic backgrounds and to inquire whether participants' demographics had significant influence on how they constructed their experience when accessing autism behavior interventions.

To enhance the credibility of the study, member checking was conducted. As mentioned earlier, the transcript of the interview was shared with the participant for their review prior to analysis. Further, the identified themes were shared with the investigator's supervisor for review and to identify areas of agreements and disagreements prior to completing a final draft of the research report.

Now to speak on the research rigor and trustworthiness. The researcher engaged in a process of reflexivity. This process involved constant reflection and critical examination of how the cultural beliefs and values of the researcher may influence the investigation process. This was important considering that the researcher shared similar cultural backgrounds with some of the participants. This similarity mostly aided the researcher to better understand participants' views on some of the questions posed in the interview. However, in some cases, participants did provide responses that deviated from the cultural values and beliefs shared between the researcher and the participants. In these situations, the researcher was careful to accurately represent the participant's view without being unduly influenced by their own bias. The researcher engaged in this process by asking clarifying questions and asking questions to probe the rationale behind certain responses provided by participants during these situations.

The researcher's field notes were a part of memoing. Highlighting and documenting the thoughts, ideas, and opinion differences that came to mind during the data collection process made up this memo process. The researcher engaged in a process of reflection, where the field notes were compared against the emerging themes in the analysis process. This comparison helped the researcher to observe the differences and similarities more vividly between the researcher's biases and the data obtained during the study. The researcher was prompted by this observation to further review literature on this topic area to gain more insight and to further engage in a more extensive discussion of the emerging themes.

Summary

This section describes the methods and approach to data collection. The study adopted a qualitative research design. The study utilized purposive and snowballing sampling techniques. Participants were sourced from various recruitment avenues, including community organizations and referrals from participants' network of friends and community members. Five families participated in the interview, which was completed over the phone. The length of the interview was approximately 45 minutes. The interview was transcribed. The analysis was done in line with grounded theory methodology. Data was analyzed in three stages of open, axial, and selecting coding. The open coding included analysis of themes into the core categories and sub-categories. The themes were further analyzed at the axial coding stage to identify relationships among the emerging themes. At the selective coding stage, a conceptual framework was developed to describe the experience of immigrant and culturally diverse families of children accessing ABA and related behavior interventions.

Chapter Four – Results

General Analysis of Themes

Participants' responses were analyzed for the purpose of identifying nuances in the different experiences of each participant. Participant P1M, a single mother, had a unique experience regarding barriers in accessing ABA services as compared to experiences of dual-parent households. These differences were articulated in terms of the participant having to undertake gendered roles typical of heterosexual parents in the service engagement process. Participant P1M indicated that her experience with accessing an autism diagnosis followed by services, was filled with difficulties and barriers, partly due to feeling that she had not been taken seriously while she was advocating for her child to be assessed. Participant P1M felt this lack of due consideration to what she was expressing may have been related to her being a single immigrant parent from a racialized minority group. For example, participant P1M attempted to convince her child's school to assist in accessing an early diagnosis of autism for her child but the school dismissed her concerns as noted in her words:

So the school treated me like I was dumb. They just downplayed everything. They seem like I was just kind of in my mind you know, like nothing was going on and so, that kind of stuff, but I knew something was up because most of her behaviors was not normal... It was difficult. and so I was just like okay... I let it go.

Participant P1M indicated that an early diagnosis would have been possible if her concerns had been duly considered by the school. Participant P1M went further and described her experience of the assessment process with such words as “disrespectful,” “frustrating,” “laughable,” “incomplete,” and “inaccurate”; all indicative of a failure to include caregiver history in the assessment and a disregard for parent education, feelings, and experience with her child's condition. Participant P1M expressed feeling excluded from the assessment

process due to the dismissive attitude of the service provider. She had the following to say about that interaction:

So, at the end of all of it, she did this assessment, didn't ask me any of my background... didn't take into account any of the work I did with her, nothing. And then she sent me that and I quote, she has a unique brain, but she cannot call it autistic because she connects well.

Participant P1 believed that she was treated disrespectfully because she is an immigrant from a racialized background as illustrated in the following:

Because I said to myself I was made to feel like I was losing my mind... And what I find is that people assumed that immigrants are stupid. They feel that we have no real education... And that's what I felt because I find that she didn't ask any of my background, didn't try to enquire about who I was before I mean if you would assess my child you need to understand the environment she is raised in.

Participant P1M indicated that she had to request another assessment by a different service provider. She described the second assessment in positive terms and noted that she was able to obtain a proper diagnosis of autism for her child, although the diagnosis came late.

For other participants, the experience of the diagnostic process was not as distressing as it was for participant P1M. This is largely because they received help from collateral systems such as daycares and physicians to access the referral and diagnostic process. This is not to say, however, that they did not also encounter challenges with accessing the assessment process. Their frustration was with the complicated assessment process that involved multiple professionals from different disciplines, and long waitlists.

Further, these different challenges that the participants experienced during the diagnosis process had an impact on their experiences when accessing autism interventions. Compared to others, participant P1M had their child diagnosed with autism at the age of nine years, whereas the average ages of the other children were between 3 and 5 years of age. Consequentially, other participants were able to access early childhood education and behavioral services, whereas participant P1M was not. Participant P1M could barely find or access services appropriate for middle-aged children. Participant P1M noted that:

Most of the resources that exist in Winnipeg... there are tons of resources when the kids are young. When the kids cross a certain age... get into like the age of nine you find the resources drop off completely. I mean it's... very minimal, extremely minimal.

Hence participant P1M recorded that they had to hire a private behavior and skills tutor for their child because they could not qualify for government funded ABA services due to the child's age.

Participants P2M and P2F, had a slightly different experience when accessing behavior interventions compared to participant P1M. These parents, P2M and P2F, had the opportunity to access ABA Early Learning Program. However, they declined because they distrusted the ABA program. ABA was just starting to be available in Winnipeg. The following quote from the participants explains their stance on the program being a novel intervention.

... I think by the time he starts attending some Provincial Schools... At that time, the ABA was still new in Winnipeg, that was 2004/5 I think it started at that time... and at that time... nobody even knew what would be the outcome. So, they just try to apply that. It was better to put him in a provincial program that was already there and to give him that chance because if he is on waiting

list and you don't get him into the program the spot is gone... And probably you gonna be again far away from getting another program...

Participants P2M and P2F indicated that due to the excessive waitlist and skepticism over the effectiveness of the ABA program, they chose to access daycare services instead. Participants P2M and P2F indicated that they received behavior interventions from workers that were sent from St. Amant program to work one-on-one with their child at the daycare. They also reported accessing home-based behavior interventions where they were provided with charts and logs to document their observations of their child's behavior and how they responded to the behaviors. For these parents (P2M and P2F), the experience of home-based behavior supports from service providers was helpful in improving their child's communication abilities.

Participants P3M and P3F had a different experience with the behavior intervention program. Following the diagnostic process, they were provided with the options of accessing ABA program at St. Amant or accessing the Manitoba Provincial Autism program. Compared to participants P2M and P2F, participants P3M and P3F did not view ABA interventions with skepticism, given their prior knowledge of ABA as an evidence-based intervention. Participants P3M and P3F reported feeling excited at their chance of admission to the ABA program and they deemed the intervention useful in helping their child acquire basic life and social skills. This is clear in the following quote.

So really for me, it was really going good. When it's time for him to take his jacket, he would take his jacket, he concentrates very well. We didn't have any issues, and we would have if we didn't get their support. They go as far as minor life skills, not just like academic, like wanting to read...just life skills. He really was doing good because when I go to pick him early, like what I

saw, if his shoes are not where it used to be, he would put it where it needs to be, things like that, until he left.

Although participants P3M and P3F reported having a positive experience with the ABA program, they still expressed disappointment over the fact that they could only access the program for a year due to age limitation.

...That's what we liked about ABA at St. Amant... It is so sad that he aged out of the program. That's the major problem we have like in Winnipeg, we don't have ABA that continues. You know what I mean because it really helped.

Participant P4F had a similar experience as participants P3M and P3F. Like participants P3M and P3F, participant P4F indicated that their decision to engage in the ABA program was informed by prior research on ABA evidence base, where they discovered that ABA is a highly rated and effective behavior intervention for autism.

I did my own research. And I found that ABA model for autism intervention is highly regarded and recommended as a very effective tool of autism intervention. And was found to have scored high across cases, where it was used. So, this reinforced my conviction. If I had doubt in it before, so I was seeing first-hand how detailed and how targeted the element of teaching, the resources were...

However, participant P4F reported that the emotional distress and the impact of autism on their family were major challenges that affected their ability to fully engage in the intervention process. Participant P4F commented that the autism diagnosis and accompanying experience of accessing intervention came to them as a shock, given that they were a new immigrant to Canada at the time. Participant P4F indicated that they were not familiar with autism prior to immigrating to Canada as there was little awareness of autism

disorder in their home country. Participant P4F experienced emotional distress navigating the ABA intervention process and it psychologically impacted their ability to engage in the ABA program.

So, for me and the mother of my child, we have sufficient educated opinion and awareness to be able to make a decision of what is going to work from an ABA standpoint. So, it wasn't a struggle for me. The struggle I had was the emotional struggle of dealing with what my family was passing through.

Participant P4F went on to share that this emotional distress was also connected to the cultural shock that they were experiencing as a newcomer. Participant P4F noted thus:

So anyways, my experience accessing intervention being in a new place, you are not familiar with the system, you are coming with a different orientation you know, but here you have to deal with eh all... you just came and you are still dealing with the issue of culture shock. And the work in different fronts of your immigration life and this one just came up. So, it was an utter devastation.

Consequentially, participant P4F initially had a low level of engagement in service process as the family was struggling with how to make sense of their novel experience. Participant P4F indicated that:

So, it took time before we were able to make sense of the different referrals, see this person, the other person on the phone... like one million persons you have to contact... one million interventions that were going on, I mean you have to make contact with...for them to start while you are await the main...let me say speech therapy, occupational therapist, so there was all those short interventions.

Accordingly, participant P4F argued that it would be insensitive for service providers to expect prompt responses and optimal engagement in intervention process from their family given the context of their experience. Participant P4F indicated that they felt as though service providers with such a mindset were holding unrealistic expectations of them. This theme of unrealistic expectations recurred in the interviews with other participants in the study including interviews with participants P2M, P2F, P3M and P3F.

Nonetheless, participant P4F, consistent with participant P3M and P3F, commended the ABA team for the emotional supports and empathy they displayed in working with their families. Participant P4F indicated that the support and empathic approach facilitated a healthy working relationship which, in turn, yielded positive intervention outcomes for his family.

And the ABA team would always come at a scheduled time to provide supports. And to check on how you are doing. And also provide guidance and directions in the areas that you are struggling. Those guys are great. They know what you are going through. So, the emotional part of it. They are just great you know. They would support you. They would tell you they know how hard it is. And that you are struggling but just do your best. They are very supportive, you know.

Participant P5M also had a slightly different experience of autism services. Participant P5M although had access to early diagnosis, she reported being unable to access the ABA program. Participant P5M felt that the ABA team were inflexible and did not accommodate the settlement related challenges her family experienced, including transportation barrier and inflexible work hours. Participant P5M had no

choice than to access the school-based behavior management program, where her child was enrolled.

The emerging subthemes from this initial stage of analysis indicated differences and similarities in the experience of the participants. This way of analysis is consistent with the grounded theory approach that emphasizes the importance of constant comparisons of participants' experiences to identify similarities and differences in their experiences in a manner that offers further insight into the dynamics of the phenomenon under study.

Research Questions

Q.1 Is the ABA intervention culturally appropriate/effective for immigrant and culturally diverse families of children with autism?

Responses from the participants on the above question indicated that for the most part, the issue of cultural appropriateness of ABA and other related behavior intervention was not a priority. Most of the participants responded with ambivalence to the question on whether the ABA or related interventions were sensitive to their cultural needs and respectful of their values. A shared theme in line with this question was the notion that ABA and similar behavior interventions neither respected nor validated the participants' cultural beliefs and values. An example is participant P2F's response to the question:

Hmm. I don't know. I can't say yes or no but I enforced it myself, that's all.

Similarly, participant P3F noted:

So, we know that yes I mean, this is how the program it is designed that way.

So, for me, I won't really put it as contradictions. I would just look at from, it's a program designed that way.

Likewise, participant P4F indicated:

They were not respected. However, they were not violated. Because the workers would always advance... they would always put forward their values associated with child development in Canada or what is required, you know.

The majority of participants in this study perceived the cultural appropriateness of the ABA program with ambivalence and they gave several reasons for this. Participant P3M believed ABA does not need to be culturally sensitive because the issues it addresses are related to practical situations that should be value neutral.

...It has nothing to do with spirituality or what our culture, associate to belief around it. So, these are not things that have to do with beliefs. They are practical things that you could do, you know, to help curb a behavior. You know something like that, our culture and beliefs have nothing to do, there are like internal feelings, internal perception, internal way of looking at things... This one is practical, like actionable thing kind of... So, it's kind of different.

Other participants felt that their cultural needs were secondary to their immediate need for supports with managing their child's behavior. These participants indicated that they would have appreciated receiving a culturally appropriate ABA intervention, provided their primary needs were adequately met, and their choices of service alternatives were not constrained by limited resources. Participant P4F shared this perspective:

So, I didn't even think in that area. That was secondary, even though that was a need but in my priority of needs, it was low. It was not even recognised.

More so, some participants felt that the responsibility of exposing their children to their native culture was primarily with the parents and that service providers bear no obligations in this regard. These participants indicated that they introduce aspects of their culture to their children based on how they deem fit. Participant P2F for stated:

...Hmm. I don't know. I can't say yes or no but I enforced it myself, that's all.

Participant P4F also related:

Because in my house, I am this strong advocate of my language. That my children hear lot of Igbo and speak. They speak you know, they understand Igbo, because three quarter of the time, I speak Igbo in my home. Like this my son now, he understands Igbo too, though he may not speak like his other siblings.

Thus, some of the participants believe that although the ABA intervention did not encourage a culture-informed approach, the service approach did not limit them from teaching their child the elements of their cultural values. Thus, the notion of cultural inclusion seemed more of a question of choice rather than necessity for some.

Participant P3F described a cultural component of ABA intervention as more of a complementary feature noting that "...it's just going to be an added... it's an icing on the cake for us really."

Notwithstanding the above points, some parents did feel that inclusion of cultural elements in ABA interventions would yield more benefits to their family. An example of this kind of perception emerged in participant P3M's words:

Yeah, so at some point, believe me or not, we had to work as a team because we had to write down the words he used at home in our language, so they put into the words that he used, right. So, they put also the words that they use at school and we just had some kinds of common meeting, common place to meet and we could try to work with him together, yeah. That was the cool, that feels like our culture also was taken into consideration.

Participant P3M indicated that they appreciated the efforts of service providers in introducing aspects of culture such as their language during the intervention. Participant P3M felt this approach validated their beliefs and values and strengthened the working relationship with the service providers.

More so, participants with an ambivalent disposition to this topic appeared to have a change of mind after the investigator described the benefits of culturally appropriate ABA services. When this happened, the conversation elicited a deeper reflection on their experience. Participant P4F, for example, indicated that they would have appreciated receiving such a service model if there was such an opportunity. In their words:

It is needs to be. It must. It should be mandated. To be culturally sensitive because one without a culture has no root. You need to be properly informed, groomed, pass through your culture to know your root. Nobody wants to lose their roots. Me, I don't want to lose my own root.

It could be inferred from the above comments that, although most participants judged their cultural needs as secondary to the ABA intervention, incorporating cultural components into the ABA intervention delivery process would benefit immigrant and culturally diverse families. Incorporating cultural features, like language, family heritage, and values, would help strengthen client-worker relationships which, in turn, would enhance parental engagement in intervention process and ultimately increase the benefits of ABA interventions. This view was echoed by Miller et al. (2019), where the authors noted that the recognition of values and traditions of families receiving ABA interventions would strengthen collaboration between service providers and the families, thereby enhancing the benefits of ABA interventions.

Q2. What aspects of ABA intervention goals, processes and outcomes do immigrant and culturally diverse families of children with autism consider important and useful to meeting their needs?

Participants revealed both differences and similarities in their appreciation of the goals, processes and outcomes of the ABA or related behavior interventions received. There was a shared appreciation for features of ABA interventions in terms of its intensity and goal targeted behavior modification approach. Participants had a sense of appreciation for how ABA and similar behavioral interventions engage parents in ongoing communication and used a hands-on approach with intervention resources such as behavior logs and charts. For most of the participants, the home-based component of the ABA program empowered them to respond to behavior challenges in the home and increased their sense of engagement in the intervention process. Participant P4F commented on this idea, noting:

It is something you do in the house. Your house becomes the learning pool. It is the learning circle. The teaching circle for you and your child. He does an activity, you go and check off, you go and rank him and how much he scored on that behavior. And then based on his score, you will be able to know how to respond to the next behavior.

This notion was also echoed by participant P3M:

But you know they were coming home too right. They were coming home as well. They did training. At least I remember a situation, the one they were talking about modelling. And then he used to scream. He was always screaming... So, we too after the lady told us about the modelling and how sometimes visualizing how it looks helps, we were like okay you know what we too would start modelling this screaming. So when he screams we too we

scream. Instead of telling him to stop, we stopped doing that and we just copy exactly what he did. And that's how that one depreciated.

Similarly, participant P2M shared their appreciation for the home-based component of the behavior program received:

They did come home... they give us materials we were able to conduct them. And also they were able to give us some strategies... At home, can take a school bag and put some books into it, right. And when he is running around. You can give him that bag and it gonna take his attention and put his attention on that bag right, and help him to calm down...

Participants gave their opinions about the improvements of language and communication skills that were attributable to the efforts of behavior intervention workers and the activities that were completed in the intervention process. Most participants viewed improvements in the areas of life skills, social skills, and communication skills as tangible outcomes of behavior interventions. This perspective gave them hope that their child would continue to gain skills. Participant P4F for example shared that,

My son has transitioned well to a lot of things that he is able to do lot of stuffs for himself. He rides his bicycle, he plays basketball, he takes his shower, he does lots of stuff for himself. And it will continue to grow like that.

Participant P2M also stated:

What was helping sometimes was the Ipad... because with the Ipad he can show you if he is sad, if he is mad, if he is upset right or if he is not feeling well..., or you can use it also to check activities...

Another subset of themes speaks to the psychosocial and cultural values of ABA and related behavior interventions that resonated with the participants. Some participants appreciated how the ABA team showed understanding, support, and empathy during service delivery. These qualities were applauded by the participants as examples of ways that service providers engaged them in a culturally appropriate way. Participant P3F for example commented that:

The ABA I mean, it doesn't necessarily say respect, but the model and the strategies actually depicts respect. For example, it depicts care. So all of the things that I have mentioned and we have talked about in terms of our cultural values, I see them in a different way with the ABA.

Participant P4F further commented that this compassionate approach to service delivery enhanced his resilience to carry on and invest in the program and willingness to follow through and engage in the ABA service process, despite some of the challenges that accompanied the service engagement process.

And also provide guidance and directions in the areas that you are struggling. Those guys are great. They know what you are going through. So the emotional part of it. They are just great you know. They would support you. They would tell you they know how hard it is. And that you are struggling but just do your best. They are very supportive, you know.

In addition, participant P2M felt included in the process during service delivery because service providers included certain aspects of her culture, such as words in her native language. This feeling of being included increased her level of buy-in during the service engagement. Participant P2M described this in the following statement.

That was the cool, that feels like our culture also was taken into consideration.

Yeah and many people who work with him, we try to do the same thing.

Choose the same language the same words, and that was helpful.

Participants shared their appreciation of the home-based component of the ABA and related behavior interventions. The provision of home-based interventions seemed to enhance the outcomes, as it meant that the skills children learnt from their schools and ABA program centers could be systematically transferred to the home context. It also empowered parents to adequately respond to behavior challenges in the home, resulting in an enhanced sense of engagement in the intervention process. Those who commended the home-based components of the behavior intervention believed that an increase in the provision of these components would enhance the benefits of behavior interventions. After all, home is where children spend most of their time. Participant P4F for example noted that:

And the ABA team would always come at a scheduled time to provide supports. And to check on how you are doing. And also provide guidance and directions in the areas that you are struggling. Those guys are great.

All the highlighted values and qualities of the behavior interventions such as empathy, mutual respect, language services, collaborative, and team-oriented service approach, were deemed to have a positive impact on parental engagement in the intervention process. In turn, with an increase in parental engagement during the intervention process there seemed to be better outcomes of both the interventions and the experience for the participants.

Q.3 What demographic and cultural features influence positive engagement in the ABA intervention process, and also allowed for a positive experience with the outcomes?

Given that most in the study reported a positive experience with ABA interventions, it is important to further analyze the common demographic features, including psycho-social

and cultural traits, that could have contributed to the successful engagement and the positive outcomes. A common theme in the study is the role that education and employment in social services played in the successful engagement.

Most of the participants in the study had some level of university education, and a significant number of the participants work in the social service field. Three of the participants had social work degrees while others had a work history in social and medical sciences. The participants commented that having a background in social sciences helped them appreciate the strength of the ABA program and the importance of behavior interventions on their child's development. The recognition of this importance motivated the participants to advocate and make informed decisions about the kinds of interventions that they would access on behalf of their child. In deciding to access ABA over other alternatives, participant P3M noted that:

...So it worked for us so, because of my knowledge, education or experience around it... Some of them were not realistically easy but because I already had the prior knowledge when I did ABA class, right, then psychology class... That's what helped a bit.

Participant P4F also shared that he opted for the ABA program due to prior research. Being evidence based reassured him that he was on the right path in accessing the appropriate intervention for his child:

I did my own research. And I found that ABA model for autism intervention is highly regarded and recommended as a very effective tool of autism intervention. And was found to have scored high across cases, where it was used. So, this reinforced my conviction. If I had doubt in it before, so I was

seeing first-hand how detailed and how targeted the element of teaching, the resources were.

Some of the participants did comment that parents with a low level or unrelated educational and work backgrounds are less likely to fully engage in the ABA interventions process and less likely to benefit substantially from ABA intervention outcomes. Participant P4F commented that:

No, they are going to be lost. They are just going to be lost. They are going to be helpless in the thing. They would just sit down and be watching them. They can't even participate. All the things they would give them to... all the program binders and activities. How are they going to deal with those stuffs. They would just give up.

Participants explained that parents with low level or unrelated educational backgrounds may lack the necessary skills for self-advocacy. Most of the participants in this study felt they could advocate for services for their child because of their awareness resulting from their educational and employment backgrounds in social sciences. They expressed concern for less privileged parents with different backgrounds than theirs, noting that these parents are more vulnerable and less likely to access appropriate interventions for their family. For example, participant P1F shared that:

This is where a lot of my concerns might be... Why I wanted to do this with you, to be part of your research is because a lot of parents aren't me. They don't have my background they don't have my experience. And so they wouldn't know how to advocate. Another parent might have been told like I was told by the specialist. She is supposed to be the best. She should know. They would not have probably gone through that. Whereas I was like

no...You don't know what you are talking about. You definitely not assisting me, and I want something more.

Participant P2M noted something similar.

And again, what I can add on that, our background. My husband worked in medical field and my sister trained as a social worker. So our knowledge helped us to know how to look for services... and how to advocate with him... and how can it be for somebody who cant even express themselves

Notably, participants believed a higher level of education and employment in the social services to be the most significant element that enabled a successful engagement in intervention process and positive outcomes for their family. Since all the participants do not have the same educational qualifications, it is inferable that parental level of awareness is an essential element for successful service engagement and intervention outcomes. Meaning that, education is more likely to contribute to a basic level of awareness that is needed to foster positive engagement in the service process to yield better intervention outcomes.

In addition to the influence of education on service engagement, another related theme is openness and flexibility. A participant in the study credited her successful engagement in the service process to the openness and flexibility of her worldview. A crucial point advanced by this participant is the idea that culture itself, does not pose a barrier to successful engagement in ABA practice. Rather, the disposition of parents towards phenomena outside their culture is what may pose significant barriers to service engagement. In a sense, it is being argued that parents who maintain a rigid approach to inter-cultural relations may have difficulty engaging in the service process with professionals from a different culture. Participant P3M for example stated that:

Another way to look at the parent in terms of response, right, some people are rigid with how they take their values, some are flexible some are open to bi-like multiculturalism or something. Some are opened to dual like they are open. So, from our own perspective we are kind of from a family where, we are a family who are opened like we are opened, we are not closed. We are not rigid. But those who are rigid, they may say no to ABA...

The above reasoning perhaps explains why parents from the same culture may experience different levels of engagement and outcomes when participating in the ABA program. Perhaps parents with a more open and flexible disposition to intercultural relations experience better outcomes and better service engagement due to their willingness to learn and relate to experiences outside their worldview. While openness and flexibility are crucial ingredients for successful service engagement, this point needs to be taken cautiously as it may be dismissive of the client's right to self-determination, equity, and social justice. If taken out of context, such a view may place unfair responsibility on parents to expand their worldview without equal recognition for the need for reciprocal efforts for cultural humility from service providers.

Another theme that emerged when analysing the data relates to the impact of environmental influences on engagement and intervention outcomes. Environmental influences such as the disposition of neighbors towards a family may be consequential to parental abilities to successfully carry out intervention strategies. For example, participant P3M recounted her experience of living with cooperative and uncooperative neighbors. P3M shared how her neighbor's reaction either reinforced or diminished her child's behavior of hitting the house wall. P3M's ABA consultant recommended that she discuss her concerns with her neighbors and request their understanding and support with the behavior modification plan. The environment impact is examined further in the next paragraph.

Participant P3M explained that her neighbor was uncooperative and would react by hitting the wall in anger whenever her child was hitting the wall. This made the child's behavior difficult to manage. Participant P3M noted, however, that after they had a new neighbor who was cooperative with them, this behavior terminated because the new neighbor did not react in anger to her child's behavior. They simply ignored the wall banging. Participant P3M's experience is a good example of how environmental factors impact parental ability to successfully engage in the ABA program. While the barrier to success is an uncooperative neighbour, imagine how more difficult it would be for newcomer families in the settlement process, who have yet to learn ways of relating to systems and individuals in their new environment.

Q.4 What challenges and barriers do immigrant/culturally diverse parents of children with autism in Winnipeg experience while working with service providers in the delivery of ABA and other related behavior interventions in home and community settings?

A common theme shared in this study relates to what is perceived as unjustified expectations that some service providers have to conform rapidly to service demands. It was expressed that such unfair expectations made participants feel negatively judged. This perceived judgement influenced parents' disposition to their relationship with service providers which, in turn, would affect their ability to fully engage in the service process. This view was echoed by participant P4F, when they shared the following:

How you take it, can never be how me will take it from Nigeria. Having lived almost half of my life in Nigeria. I wasn't born here and I come here and you expect me overnight, my lived experience in Nigeria, you expect me to just do a switch and begin to see things from your own value.

This view was also shared by other participants. They believed that the challenges of settling into a foreign environment and then the accompanying demands that follow when one's child is diagnosed with autism, could overwhelm immigrant parents, and make it difficult for them to promptly respond to service demands. Considering this, it would be more realistic to expect immigrant parents to slowly progress towards full engagement in the interventions than expect them to wholly embrace it from the beginning. Participants indicated that patience from service providers along with supports for the families would go a long way to build the motivation and resilience needed by immigrant parents for a better engagement.

Furthermore, participants expressed concern about the barriers that the attitudes and biases of some service providers could pose to establishing a positive working relationship with parent. Some participants reported perceived stereotypes and discrimination owing to their racial and cultural identities. Participant P1M, for example, believed that there was a complete disregard for her experience or role during the process of diagnosis by some service providers. Participant P1M felt that this lack of recognition was connected to stereotypes that some service providers could have towards immigrants from racialized backgrounds. Participant P1M stated:

Because I said to myself I was made to feel like I was losing my mind... And what I find is that people assumed that immigrants are stupid. They feel that we have no real education... And that's what I felt because I find that she didn't ask any of my background, didn't try to enquire about who I was before I mean if you would assess my child you need to understand the environment she is raised in. Because that obviously ...you know they say nature and nurture, and nurture plays an important part in everything. She didn't ask me a single question.

Other participants expressed similar concerns and indicated that some service providers tended to be imposing in their approach to service delivery. This style of approach, also referred to as prescriptive style, risks causing parents to feel that they are given directions to follow without due regard for their views and feelings about the decisions being made. Participants felt that this prescriptive style left them feeling as though service providers were mandating them to accept a specific course of action without providing them with the liberty to choose among other viable alternatives. This feeling was identified as a barrier to successful engagement as some parents could be uncooperative as a way of resisting this domineering attitude. Participant P4F offered:

Every person that comes in contact with you needs to be very culturally sensitive. In whatever gesture or in whatever interaction they are initiating with you because you are coming from a different world. Let them not expect that they said ABC, that because they said ABC, you are going to say DEF. I can say ABC and you say XYZ.

Some other themes that emerged in this domain relate to macro level issues that hinder access and successful engagement for immigrant and culturally diverse parents of children with autism. One major barrier identified by participants is the limited admission space in the ABA program. Some of the participants articulated being unable to access the ABA program because there was no space available for their children. Other participants reported having to be on a long wait list to access the Early Learning ABA program. A crucial factor identified by the participants related to the age limitation of the ABA program, such that children above the age of six years old are not able to enroll in the program. The implication for some of the participants

was that their children could only stay in the program for a short period of time, thus making it difficult to fully engage and enjoy optimal benefits.

This limitation disproportionately affects immigrant families given that immigrant children are more likely to receive a late diagnosis of autism as opposed to their Canadian counterparts, thus reducing their chance of an early entry into the ABA program. Participant P3M spoke to this in the following:

St. Amant age out year is six years and he only got access to St. Amant when he was five. Then he did the early learning program with them. And six years you know, they have limited stay, so he aged out of the service. He was only left to just consultation services with school. Nothing much. Like we had for one year with them.

Other participants commented that they had to look for other forms of behavior therapy as they were unable to get their child enrolled in the ABA Early Learning Program due to late autism diagnosis. Participant P1M for example, indicated that her child was diagnosed at the age of nine years and so getting into the ABA program was impossible no matter how she tried. She had to hire a private behavior and life skills educator to work with her child.

Most of the resources that exist in Winnipeg... there are tons of resources when the kids are young. When the kids cross a certain age... get into like the age of nine you find the resources drop off completely. I mean it's there. Very minimal, extremely minimal. Cuz I even called St. Amant Center because there were no services for her.

It does seem that immigrant parents are disproportionately affected by policies around service access. Age limitations and structural barriers that include long waitlists, delayed

diagnosis, limited program space, and limited alternatives to programs all negatively impact immigrant families. Some of these factors were identified by other scholars including, Sritharan and Koola (2018), and Millau, Rivard and Mello (2018). Now to look at the experiences of this study's participants to determine if policies negatively impacted them.

Participants reported that any successful engagement is hampered by the complicated referral process for available programs. This barrier is even more problematic for parents with limited education and awareness on how things are done in Canada. They are likely to be lost while navigating their way through the many steps before accessing the ABA program. There are multiple assessments required, and these assessments must come from various sources including psychologists, audiologists, occupational therapists, etc. The impact of this complicated referral process was described by participant P1M, noting that

I called everywhere there were no services, And then the other ones you would have to get referrals, and some of them even though they exist you would still need to a get referral... And that is not common knowledge to some of them.

Participant P4F also shared his experience of the complicated referral system, noting:

So it took time before we were able to make sense of the different referrals, see this person, the other person on the phone... like one million persons you have to contact... one million interventions that were going on, I mean you have to make contact with for them to start while you are await the main...

As noted by the participants, immigrant parents may have difficulty navigating the complicated referral processes and more likely to experience hindrances to successful engagement. This is especially so when there is lack of adequate support to help them navigate the process. In line with this notion, Miller et al. (2019) commented that criteria such as program participation requirements may engender inequitable access to ABA

interventions for culturally diverse population, where such requirements do not adequately accommodate the needs of culturally diverse families that are navigating the process to access services.

Another barrier to successful access and engagement in ABA and related behavior interventions is the inadequate resources provided by some schools. Participants indicated that schools became their major option for accessing behavior intervention services once their children aged out of the ABA Early Intervention program. Participant P3F expressed this concern, noting:

That's another thing. There's not a lot of options to choose from in terms of supporting children or a child with autism not a lot of options just St. Amant we have and after then we been left to the mercy of the school, nothing much.

Further, participants expressed concern that some of the schools are ill-equipped to provide appropriate behavior intervention programs. Consequently, parents are having to move their children from one school to another with the hopes of finding a suitable school program that would meet their children's needs. A participant shared that their child was bounced from one school to another and excused from multiple daycares due to a lack of appropriate resources and inability to meet their child's needs. This lack of access to a stable educational environment disrupts the child's educational and social development. It also affects the parents' ability to develop a stable relationship with educators along with a successful engagement in a behavior intervention plan. A possible consequence of the frequent changes of schools is the breakdown of relationships with existing service providers. Participant P2F commented about this lack of adequate resources in most schools, sharing that,

Wherever he find the school which they are not prepared, they do not work with the special needs, it became a problem... he lost many things, everything he had already achieved, the use of ipad and even also expelled from school.

More problematic is that only a few schools have provincial funding for the school-based behavior program. Participant P2M related that due to limited enrollment space in these schools, they had to actively advocate on their child's behalf before he was admitted into one. The following is a snippet of the interchange with participant P2M telling their experience when trying to access an appropriate school program.

The Oakenwald [School] is an elementary school for the program they called IPSA. Are you aware of that program? yeah... and it is interdivisional program for students with autism... So, there's only three high schools in the entire province so to get in is a chance. To have opportunity to attend these kinds of schools, it is very hard if I can say... because the demand is high, the schools are few.

For immigrant families, the scarcity of adequately resourced schools implies that a significant number of their children will not be enrolled at an appropriate school due to socio-economic barriers that immigrant families experience. In addition, immigrant parents who lack the ability to advocate for their child will not have success accessing the appropriate school. Participant P2M, for example, shared that her family was able to access some of these school-based programs because of their relentless efforts in advocating for their child.

We have to fight for him to get all of those programs it wasn't easy... Most of the times I think there is high demands and few programs. Also, there is a kind of like, I can say, educational discrimination. because maybe there was no

need of giving him services which he needs and has the right on. We have to fight with them to get him into all of these programs.

It is understandable that immigrant parents who are dealing with settlement challenges and have yet to adjust to their new environment may experience more difficulty enrolling their child in schools that provide relevant behavior interventions. Newcomer families for example, may lack adequate information about eligibility criteria to these schools, considering that they are new to Canada and are still in the process of familiarizing themselves with the operations of social services and the education systems. This barrier to appropriate school enrollment often results with parents not being able to successfully engage in ABA or other related behavior interventions. It is unfortunate that their children are unable to have equitable access and experience the benefits of the behavior interventions.

Another common theme related to the barriers participants encountered is the lack of appropriate supports. Some shared they had a feeling of helplessness in Canada, due to the absence of relatives who could have supported them with what they needed to fully participate in the programs. This absence of familiar supports is understood within the context of a collective culture in home countries, where families and relatives work together to raise each other's children. For example, Participant P3M noted:

As immigrants, now, being in a strange place, in a strange land where we have come to build this thing from scratch, like our social network and don't have as much as we do back home. It is even now more difficult like because if it was back home, your neighbors, your friends, your relatives your sisters and brothers will help in shaping or even helping with okay like this ABA is provided back home and you have a cousin who lives with you or your neighbor you will have more supports. You know what I mean.

Familial support is important because it enables parents to consistently engage in the ABA program. Participants indicated that consistency is key to successful outcomes of the ABA interventions and parents need to be always ready to respond constructively to specific behavior based on recommendations from service providers. However, many maintained that it is almost an impossible task to be consistent and available to attend to every behavior situation due to competing caregiving and family demands. Participant P3F for example stated that:

While we would say that it is not realistic is that. Not every time we are there by him when he is doing the same thing. When we are there, you know as a family, of course, we have a lot going on. Things that would have to be done. The home chores and things like that, right. But when we are there with him, yes, we are able to implement those strategies and then stop the behavior. But when we are not readily there, at that point in time.

The participants mentioned that they would have been more consistent at engaging in the program if supports were adequate. Respite service was a major source of support that participants appreciated although they mentioned that respite was limited and inadequate to meet the scope of needs of their families. Participant P3F for example, shared that:

Even now we get some supports for maybe like respite. It's more like 8 hours in a week. So, a week of 24 hours x 7 right... we are only getting supports for 8hours that is funded.

Participant P4F expanded this issue further, noting that cultural differences in values affected his relationship with respite workers. The cultural differences were mostly with Caucasian respite workers. Because of the differences, there would be a turnover of respite workers. Participant P4F noted that:

Respite was a big issue, given cultural dynamics. You know we are settlers here. And then culture, anybody that begins to deny the impact, the biases and his biases or her biases, is not being true to him or herself. So, it was always a struggle that we get respite and they come they do two days with us and they disappear. Because they are not comfortable with our cultural background. Because these are Caucasian group of workers. They are not comfortable. And so, it was a struggle that there was a high turnover of respite over the course of intervention. Sometimes we stay very extended time not having any support... any respite.

Alternatively, immigrant families could access supports from members of their ethnic communities. However, some indicated that this can also be difficult to access due to the perceived stigmatization of disabilities in some ethnic communities. Participant P3M for example, stated that they keep a small circle of friends to avoid judgement and negative perceptions of their family by fellow ethnic community members. This kind of closed family system, and the resulting isolation, makes it more difficult for immigrants to access culturally appropriate supports and resources.

To summarize, there is a relationship between the lack of adequate supports (familial and respite) and consistency in service engagement. Parents lacking adequate supports are less likely to be consistent in their engagement in the service process. In turn, low parental engagement may impede successful outcomes of ABA and other related behavior interventions.

Other areas of need affecting parental engagement include lack of language services along with other settlement-related challenges. Participants noted that interpreter and translation services are crucial to successful engagement in ABA interventions, given the

limitations that language barriers could place on the ability of parents to communicate with service providers and to follow through with service recommendations. Participant P2M, for example, stated:

And again, for the newcomer... It doesn't matter they speak a little bit English or not, they always need an interpreter. We never had an interpreter. No, we never had to ask. I think it for new people who know English as Second Language they should always give them a chance to have an interpreter... Because sometime, it's not easy to understand the content root of the words they are using.

In addition, participants mentioned that service providers need to be mindful of the context of the experiences of immigrant and culturally diverse families. It was noted that some of the dynamics that characterize these families and service providers include differences in worldviews, orientations, and values. These differences may pose barriers to successful working relationships between them. It bears mentioning, however, that participants who engaged in the ABA Early Learning Program at St. Amant, did not feel that values differences had any significant impact either on their engagement in the intervention process or on the intervention outcomes. However, other participants did report a strain in relationships, owing to a clash of values with service providers including school staff, medical practitioners, and child protection workers. Given that behavior planning for children affected by autism requires a comprehensive and integrative practice from a multidisciplinary team approach, the actions of service providers from various professional fields equally affect the success of engagement in the application and outcomes of the behavior intervention. Thus, a conflictual relationship with other service providers involved in the process may demotivate parents that are otherwise willing to engage. Participant P2M for examples narrated her experience with child protection workers:

Basically, most of the things they were teaching us is for mainstream. So, culturally, we have our own ways of taking care of our special needs people. So, we see that we were forced to follow Canadian way of taking care of special needs people. I can give you example, they told us that they gonna take him away when he was six. They tried to take him away when he was six... and we had to fight until he was 14... because They wanted to place him in care... it can be for us our liberty... we were just telling them you know our job back home is taking care of our people with special needs as much as we can, so it was always you feel like we are being called to follow the mainstream way of taking care of our son.

Participant P2M believed that attempts to apprehend and bring her son into care undermined her cultural beliefs which require her to take care of her child to the best of her abilities. This decision to apprehend was seen by the participant as a value clash. The service providers felt apprehending the child would relieve parents of the stress of caring for their child because of the severe behavior problems. Participants P2M, however, perceived the situation to mean that service providers were trying to force them to choose relief over fully caring for their child with special needs. This is their cultural expectations, regardless of the challenges present in parenting. Fortunately for participant P2M, she indicated that she was able to advocate to have her child remain in her care, otherwise, she might have been unable to successfully engage in the behavior intervention plans with other service providers if her right to care for her son had been relinquished.

Q.5 What kinds of supports and resources can be useful to mitigate the challenges and barriers that immigrant and culturally diverse families of children with autism in Winnipeg experience as they access ABA interventions?

Participants in the study noted a few areas in which resources and supports could be channelled to that would enhance the ability of parents to successfully engage in ABA and other related forms of behavior interventions. A major aspect of these resources pertains to in-home support. This is due to immigrant families lacking access to adequate familial supports. Most of the participants indicated that respite is crucial and something that could be offered to immigrant families. This would make a significant difference in their ability to engage better in the intervention process. What participants identified was a specific form of respite; one that allows more control on how the hours are utilized as well as when they are used. Some of the participants indicated that they would prefer to use the respite provision to hire a behavior coach to work one on one with their child in the home. Participant P1M for example, indicated that she benefitted from using the respite allowance to hire a behavior intervention worker to teach ABA strategies and life skills programs to her child during respite hours. Participant P1M stated that:

So what I would like is that if they really define that respite... and maybe take away that old time respite and just call it skills maintenance which will allow them to give more hours and then have somebody, like I would be able to hire and do my own training because of my background.

Participant P3F requested a similar respite model, noting:

So if we can get ABA support, get someone who is trained in ABA to come to the home to help in terms of some of the things that we have described and when we are busy with other life things that we need to do

Provision of respite for use toward the ABA program will benefit immigrant families considering that many immigrant families were unable to access the Early Learning ABA program. Expanding the hours of respite and terms of use would enable parents to hire their

own behavior service provider to offer ABA services. This would also be beneficial to the families because the intervention is delivered in their home. Parents would have the flexibility needed to deal with settlement related challenges while engaging in the intervention process. Additional supports and services relevant to immigrant families that were highlighted during the interviews are discussed in the responses to the next question which addresses the recommendations for service improvement for immigrant families.

Q6. How can the findings from research be integrated towards developing a culturally effective framework for delivering ABA interventions to immigrant and culturally diverse families of children with autism?

This question probes ways through which the information obtained can be used to inform the development of a culturally appropriate framework for the delivery of ABA and other related behavior services. The context of the participants' experience as immigrant families imply that service planning should incorporate key features that could alleviate the challenges and barriers that hinder successful engagement and therefore, successful outcomes. Language consideration is one of the major themes that emerged in this study. Although participants spoke English fluently, they had indicated that incorporating words from their mother tongue when delivering services would enhance the cultural appropriateness of interventions. Some considerations for language when English is not the family's mother tongue would include making provisions for an interpreter and translation services. Participant P2M mentioned the importance of introducing certain words from the parent's indigenous language into the vocabulary that service providers use while engaging with immigrant children. This style of engagement as noted by participant P2M makes families feel appreciated and increases the cultural competence of service providers.

Participants also voiced a need to be included in service planning. Some of the participants felt as though service providers underestimated their relevance and knowledge as parents. This perception of service providers' attitudes left some feeling as though service providers were imposing their own views on them, with little regard for how the parents felt about the intervention.

Participants further expressed a need for ABA and related programs to expand the provisions of home-based interventions. Given that some immigrants are still in the process of adapting to systems outside their micro-environment, it would be a significant advantage for these families if they received home-based interventions such as increased respite hours and in-home ABA consultative services. Several participants expressed feeling abandoned due to limited in-home supports. The impact of inadequate home-based services is more acute for immigrant families considering that some of these families are far away from their relatives.

In addition, service providers need to constantly reflect on their attitudes and biases while engaging with immigrant and culturally diverse families. Some of the participants did report that they enjoyed working with service providers who had an open mind and showed a willingness to learn about their cultural ways, family history and backgrounds. In other words, they showed a genuine interest in getting to know them. Service providers need to avoid making unfounded assumptions about the needs of families without allowing families a chance to express what they believe their needs are. Participant P5M, for example, stated that she was not aware of her eligibility for respite services until she was informed by another parent about it. Participant P5M commented that when she questioned her worker on why she was not told, the response was that they assumed Participant P5M already knew about it and was probably not in need of it. A key point to consider and also noted by Participant P5M, is that some immigrant parents lack the confidence to self-advocate for their family because of

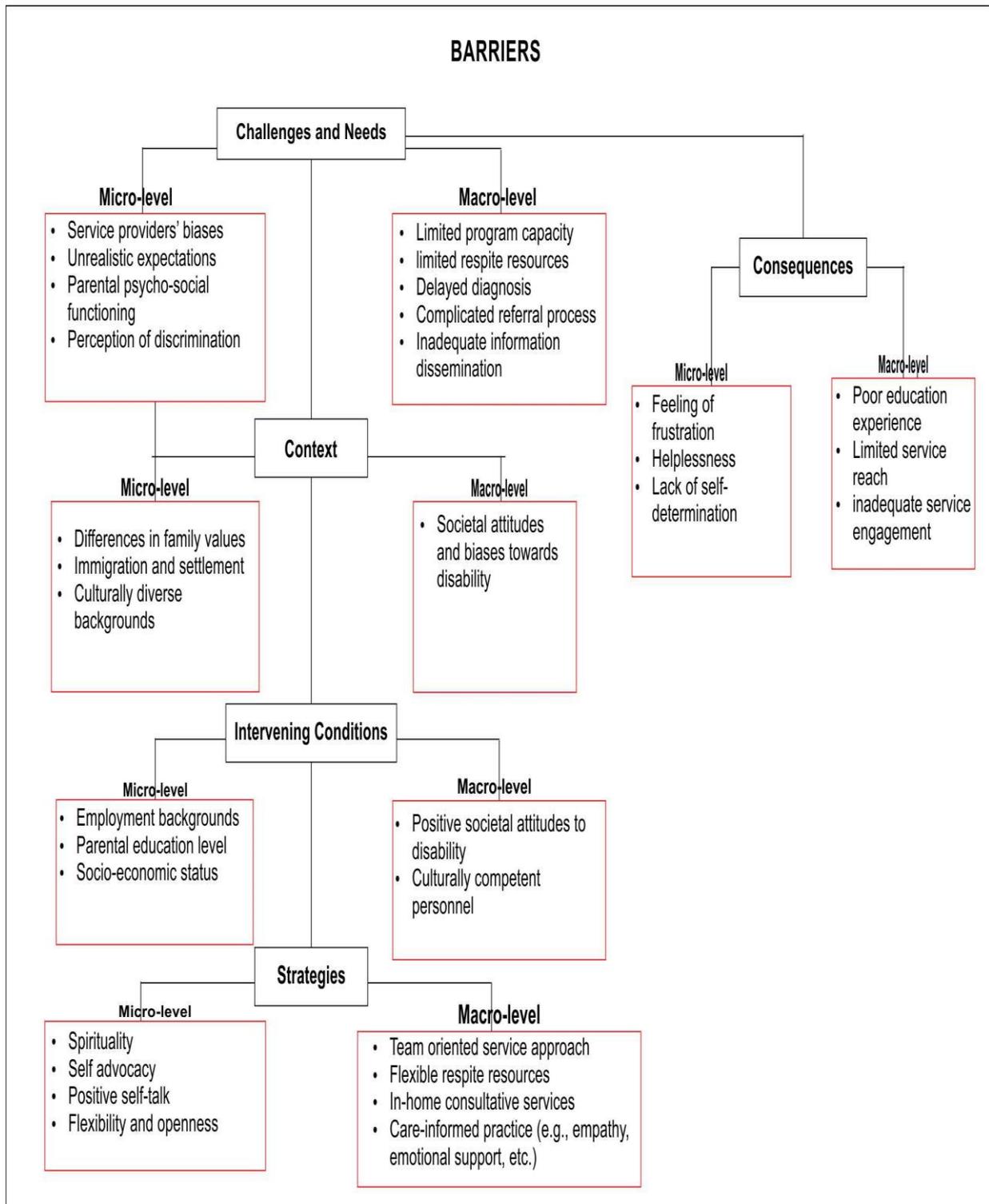
the influences that adjustment challenges would have on their confidence level. Hence, service providers need to be sensitive to the direct and indirect ways through which immigrant families may communicate their needs. They also need to understand that some immigrant parents may be too shy to express their needs. Service providers could empower such parents by simply providing them with relevant information on the various resources available and by creating a safe space for immigrant parents to comfortably express their needs.

Overall, participants expressed a need for the expansion of service options and platforms. Participants reported, for example, that St. Amant offers the only ABA Early Intervention Program in Winnipeg. Hence, participants that do not qualify for ABA services at St. Amant have no other option to receive ABA services. More so, once children have aged out of the ABA Early Learning Program at St. Amant, there are no additional ABA programs except in cases where the parents could afford to hire a private behavior tutor to provide some basic life skills and behavior services. Participants expressed a need for an expansion of ABA service platforms and for easing the referral and eligibility criteria to make ABA services more accessible to immigrant and culturally diverse families.

Conceptual Framework:

The conceptual frameworks adopted in this stage of analysis helps to further describe the challenges experienced by immigrant and culturally diverse families of children with autism accessing ABA and other related behavior interventions. The figure below is an illustration of this description that presents a conceptual representation of the themes that emerged in the study.

Figure 1: Conceptual Framework



The points contained in Figure 1 could be further synchronized into a conceptual framework in line with the grounded-theory approach. This analytical framework helps to unpack the complexities of the experience of immigrant and culturally diverse families seeking services for their children with autism. The complexities can be described as the

challenges, contexts, strategies, and consequences of the various strategies employed to find services. The adoption of the eco-systemic perspective further helps to conceptualize how the various components and complexities in the experience of the phenomenon interact at various systemic levels to shape the realities of the experience of immigrant and culturally diverse families accessing ABA and related behavior interventions.

Challenges and Needs

Data from the study suggests that the challenges and needs inhibiting the successful engagement of immigrant families in ABA and other related behavior interventions are mostly macro-systemic issues. Examples of these issues drawn from the study include a complicated referral processes, the limited program capacity, an age barrier on ABA accessibility, delayed diagnosis, limited respite resources, inadequate language services, and inadequate information dissemination. See figure 1 for an illustration of these themes.

Within the micro systemic level, productive engagement between immigrant parents and service providers may be hampered by some influences revealed by the study's data. These influences include the biases and unrealistic expectations of service providers. Participants reported that their inability to meet some of these expectations made them feel that they were being judged harshly by service providers and that service providers were trying to impose their own values on them. Some participants further identified discrimination due to a perception of bias in the service providers' attitudes toward the parents. This perception of bias by service providers was expressed in their attitudes according to some participants and this, in turn, was enough to not want them to fully engage in the intervention.

Immigrant families have additional challenges because of their migration from their home country to Canada. It may be that these migration challenges have impacted on the

parents' psychosocial functioning which further lessens the likelihood of successful engagement in the intervention process. Participant P5M noted that due to being a newcomer in Canada she was too shy to even ask questions of her case worker about what service entitlements were available to her. Her case worker failed to provide her with such information, assuming that Participant P5M should have known to ask. As a result, participant P5M was unable to participate fully in an ABA intervention as she was unable to access available supports to help navigate the service process. Speaking retrospectively, participant P5M indicated that she may have been able to fully engage in the ABA program had she been able to self-advocate for needed supports and resources.

Context

Although some of the highlighted challenges also affect mainstream Canadians, immigrant families experience these challenges in unique contexts. See figure 1 for themes relating to the contexts of the experience of immigrant families. These families experience challenges with engaging in the ABA intervention process due to the barriers that are settlement related. For example, although a delayed diagnosis is a general problem that could affect mainstream Canadian families, immigrant children are more likely to experience a delay in obtaining a diagnosis of autism because their parents may have greater difficulty navigating the care system. As noted by one of the study's participants, their child was unable to qualify for the ABA Early Intervention program because their child received a diagnosis of autism after the child already passed the age cap for eligibility into the ABA early learning program.

Immigrant families are often from culturally diverse backgrounds and along with that, they possess culturally diverse worldviews and values. Although most participants in this study reported that cultural differences were not significantly influential in their engagement in the ABA process, some participants did report that value differences contributed to

conflicts in relationship with service providers. This was especially so where participants perceived service providers to be holding unrealistic expectations and biases towards them.

At the macro-level, as depicted in figure 1, participants contextualized their experiences against a backdrop of societal attitudes and biases towards having a disability in general. These biases contribute to a lack of significant policies to ensure adequate funding for disability services and resources. Participants, for example, complained of limited respite resources and a lack of relevant ABA interventions for middle aged children and older. Some participants commented that these gaps in service provisions resulting from inadequate funding reflect a bias at the structural level whereby disability matters are not accorded the same value given to other socio-economic issues such as defence, infrastructures, etc.

Intervening Conditions

The data from this study indicates that certain conditions (see figure 1) mitigate the influence of service-related barriers and challenges. Micro-systemic characteristics such as the level of parents' education was noted to be a significant element that influences successful engagement in, and the outcomes of ABA interventions based on the data obtained from the study.

Participants with post-secondary education in social sciences, and/or employment history in social sciences field, for example, all reported that their social sciences backgrounds played a huge role in their conceptualization, understanding and engagement in the ABA process. The prior knowledge and level of awareness of these participants helped them understand the benefits of the ABA intervention as well as the rationale for the principles, strategies and approaches that were adopted in the program. This level of awareness and education made it possible for these participants to overlook the impact of

cultural differences in the delivery process of the ABA intervention, because they were able to adopt a flexible and open-minded approach in their engagement with service providers.

The above finding does not, in any way, suggest that immigrant parents without education or employment history in social sciences field will not successfully engage and benefit meaningfully from their engagement in ABA intervention. It however, draws attention to the need for psychoeducational programs that would prepare immigrant parents who are less educated and have no prior awareness about the ABA and other related behavior interventions. Such preparatory programs would help immigrant parents understand the value of the ABA intervention and how to reconcile the value differences that they may experience in their engagement in the ABA process.

In addition, service providers' cultural competence is an intervening element in mitigating the challenges that immigrant and culturally diverse families of children with autism experience. Miller et al (2019), for example, echoed this claim in their study, noting that such elements as cultural humility, and cultural responsiveness help create a collaborative and positive relationship between service providers and culturally diverse clients, thereby resulting in positive service outcomes. Similarly, participants in this study, commended the ABA team for their display of empathy, patience, and emotional supports throughout the intervention delivery process. These values helped nurture a positive working relationship that sustained parental engagement in the ABA intervention process. Participants also saw this approach to service delivery as being culturally responsive and sensitive to their plights as immigrants in settlement. Therefore, it could be said that service providers who practice from this stance may elicit a more productive engagement of parents in the ABA process, whereas the absence of these qualities may occasion a strained and distrustful relationship with immigrant parents, further inhibiting their willingness to fully cooperate and engage in the ABA intervention process.

Further, the socio-economic status of immigrant families could become a barrier to successful engagement in the ABA process. Low-income immigrant families for example, may experience significant blocks when trying to access service. These blocks include transportation and inflexible work hours that may restrict their availability to engage in the ABA interventions. Participant P5M, for example, shared that her family could not engage in the early learning ABA program due to transportation barriers and both parents working inflexible hours. Other participants also shared their challenges with being unable to hire a private behavior therapist to work with their child due to limited income. Interventions for these families requires a systemic approach that considers how parental immigration status impact their family's socio-economic status and how these influences often affect their successful engagement in the ABA intervention process.

In addition, other macrosystemic elements, as illustrated in figure 1, such as community attitude to having a disability may affect successful engagement in the intervention process for immigrant families. Considering that having a disability is mostly an issue of stigmatization in some of the immigrants' home countries, their willingness to fully engage in the service process may be hampered by their fears of judgement by community members around them. Participant P3M for example, mentioned that because they lived in a townhouse during their early phase of immigration into Canada, successful implementation of some of the ABA strategies recommended to them was dependent on certain environmental influences such as having a cooperative neighbor. For this participant, having a cooperative neighbor who would not react harshly to their child's behavior issues made it possible to reduce any external influence that could elicit unwanted reinforcement of the behavior that the parents are trying to terminate. Such a feat was almost impossible when the family previously had an uncooperative neighbor. This finding draws attention to a need for awareness at the communal level about ways through which community members could

support parents of children with autism to navigate the challenges that may hinder their ability to follow through with interventions.

Strategy/Coping Mechanism and Outcomes

Data from the study revealed that immigrant parents as well as service providers use various strategies to meet the challenges that they experience during the intervention phase. See figure 1 for an illustration of the various strategies reported by participants. One strategy indicated by most of the participants was self-advocacy for services that otherwise may not have been provided. Participants in this study mentioned that demands to access services, including ABA, were excessive. To make it even more difficult, available program opportunities were limited. Hence, self-advocacy became a crucial tool in their repertoire, especially as they were more likely to experience barriers to service access due to settlement challenges. Participants reported being able to access services such as respite, referral for diagnosis, home-based behavior intervention, and other services mainly because of their relentless efforts in advocating for better services for their family.

This finding draws attention to the need to empower immigrant parents to acquire skills that can enhance their ability to self-advocate for their family, considering that some participants reported they were unable to self-advocate, and they believed this was the reason that they were unable to access appropriate services. This point is crucial considering that a participant commented on how the experience of immigration challenges diminished her confidence in having the ability to engage with service providers from a strength-based position; one that would allow her to advocate for her family. Another participant commented about having to request the help of a public officer to write a formal letter before she was able to access services that she had previously been requesting. It is no doubt that empowering immigrant parents with tools for self-advocacy promotes self-determination, which is a core value within the social work field. Hence, social workers engaging with immigrant families

of children with autism can explore ways through which they can foster self-advocacy skills for immigrant parents who are accessing ABA and other related behavior interventions to help these parents maximize the benefits of the behavior interventions.

This study also revealed other coping skills, as illustrated in figure 1, cited by participants include spirituality and positive self-talk. These coping mechanisms were noted by some to be crucial in sustaining their engagement in the ABA intervention process. A reason for utilizing these strategies, as noted by the participants, is that the ABA service process and experience of autism challenges overwhelm them and so they need to utilize self-coping strategies to help them successfully engage in the intervention process. Participants, for example, mentioned that spirituality helped them make sense of their experience and gave them hope to look forward to having positive outcomes from the intervention experience. This use of positive self-talk, as noted by some participants, helped them become resilient in confronting the challenges they experienced in the intervention process. Some participants who utilized positive self-talk also commented that they were able to support others in similar situations by helping them rethink their experience in empowering ways. It would be beneficial for service providers to find ways of facilitating the use of these strategies to help sustain caregivers' motivation when engaging in the behavior intervention process and building caregiver resilience to manage the challenges of autism in a self-empowering way.

Openness and flexibility are other strategies that participants identified as crucial in sustaining their engagement in the ABA intervention process. The values of openness and flexibility helped participants expand their worldviews towards appreciating the values and principles of the interventions. Participants who reported having a positive working relationship with service providers were with those workers who showed openness and flexibility to understanding the family's worldviews and value system. This openness and

flexibility were noted by participants to be important in their engagement in ABA intervention process.

Another consideration is that service providers model values of openness and flexibility in ways that inspire immigrant parents to expand their own worldviews and make sense of the interventions that they are receiving. An example of this strategy was noted by participant P2M who indicated how service providers gave opportunities for them to include vocabulary from their native language into the behavior intervention process. This openness and flexibility displayed by service providers as noted by participant P2M resulted in them feeling like their values were respected in the intervention process and enhanced her willingness to further engage in the intervention process.

Further, having a flexible use of program resources were noted to be a helpful strategy in maximizing the benefits of available services. Participants commented that they were able to access behavior interventions through provisions under a respite scheme that allows them to use their respite funding to hire private behavior tutors that could work with their child in their home environment. Some participants noted that they would not have been able to access behavior services if not for this flexible provision. This allowance was viewed by participants as a way of promoting self-determination in service delivery and expanding more options for service accessibility.

Participants reported that when service providers consulted with them, it felt like a team-orientated approach, and it was experienced as incredibly supportive. Ongoing consultation and supportiveness within the home environment were noted by participants to be remarkably effective in helping them engage successfully in the intervention process. Participants shared that these strategies made them feel like they were not alone in their struggles. More so, participants noted that in-home consultation produced more culturally

relevant and realistic recommendations from service providers given that the recommendations were borne from the service provider's direct observation of the interactions of family dynamics and the behavior challenges that they experience.

Participants requested more of the home-based ABA intervention supports and they remarked that there are more positive outcomes of these strategies. Participants commented that the gains of ABA and other related behavior interventions were mostly appreciated for the enhancement of their child's speech and communication skills, as well as life skills. Participants reported that improved mastery of the above skills by their child would give them, as parents, a sense of assurance that their child could be self-reliant in the future should parents become involuntarily absent from their child's lives due to uncontrollable life circumstances such as death. Participants considered that teaching speech and communication skills as parts of home-based components of ABA interventions is beneficial to their family given that parents can more easily participate in this process. Service providers could also observe communication patterns in the home environment and adapt these ways of communication into the intervention delivery approach.

Consequences

There were negative consequences resulting from lack of adequate coping resources and mechanism for some families. See figure 1 for an outline of these consequences. Some participants expressed feeling frustrated and helpless due to lack of appropriate resources to meet the behavior challenges that they experience when parenting their children. A common theme that participants expressed was the feeling of a lack of self-determination on decisions pertaining to ABA service delivery and other related behavior interventions. This lack of self-determination is linked to the limited options exist in Winnipeg for families needing access to such specialized programs. St. Amant, for example, was noted by participants to be the only center where one could access the ABA Early Learning Program. No intermediate ABA

program exists for children who are over the age of six years. Participants also reported that there are no private ABA program centers, therefore public schools seemed to be the only alternative for parents wishing to access coordinated services that include some behavior intervention. This claim is based on the view of participants on service options in Winnipeg. It should be noted that a study by McLaughlin and Schneider (2019) found a consistent view and advocated for access to behavior interventions outside of school programs.

Even though public schools offer some resources, participants reported difficulty in enrolling their child in schools that are resourced to meet their needs. Participants reported that only a few schools in Winnipeg have the funding and resources to accommodate the children's needs. As such, participants reported that they felt compelled to accept whatever resources were provided even if they were not appropriate for their peculiar needs. Consequentially, participants noted that their child bounced from one school to another, and their family had to relocate neighborhoods to access educational services for their child.

Another reported issue was the lack of acquisition of appropriate life and social skills. Participants saw this as a direct result of the lack of ongoing ABA interventions. One participant reported how they observed remarkable progress in their child's development of life and social skills only for this to be stalled due to the lack of access to ongoing behavior services after their child aged out of the ABA Early Learning Program. For most participants, acquisition of essential life and social skills are priority service needs for their child. Participants indicated that the lack of resources in this domain makes them worried about their child's future when they (parents) are no longer able to provide care. Interesting that the participants only identified death as the phenomenon that would prevent them from caring for their child.

The table below illustrates the participants’ experience of positive outcomes of ABA interventions and some of the factors that participants believed contributed to their experience of positive ABA intervention outcomes.

Table 3: Positive Outcomes of ABA Intervention

Positive Outcomes of ABA Interventions	Factors Contributing to Positive Outcomes of ABA Interventions
❖ Improved communication abilities/social skills	❖ Skill-oriented model of ABA interventions
❖ Improvement in developmental skills e.g., locomotive skills	❖ In-home supports to families
❖ Acquisition of life skills e.g., personal care	❖ Positive parental engagement in intervention process
❖ Decreased behavior challenges	❖ Service providers’ responsiveness to clients’ psycho-socio needs
❖ Improvement in parent-child relationship and communication	❖ Collaborative and cooperative relationship between service providers and families

❖ Positive education experience	
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The table below illustrates the participants’ experience of negative outcomes of ABA interventions and some of the factors that participants believed contributed to their experience of negative ABA intervention outcomes.

Table 4: *Negative Outcomes of ABA Intervention*

Negative Outcomes of ABA Intervention Experience	Factors Contributing to Negative Outcomes of ABA Intervention Experience
Stalled growth in developmental/social skills	Discontinued ABA services due to age limitation
Lack of self-determination	limited program options

Feeling overwhelmed	Parents deemed ABA service demands as excessive
Parents' feeling unfairly judged	Service providers lack of recognition of effect of settlement challenges on parental engagement in intervention process

Summary

This section describes the study results. Findings from the data analysis revealed that ABA intervention is adaptable to cross cultural contexts such that immigrant and culturally diverse families of children with autism can benefit from the treatment. The findings further revealed that systemic barriers affect the chances of maximizing positive ABA outcomes for immigrant and culturally diverse families of children with autism. The data analysis also depicted issues for considerations towards mitigating the barriers preventing successful access to ABA services and experience of positive outcomes, where such considerations include language services, respite services and early diagnosis, among others.

Chapter Five – Discussion of Findings

The findings from this study are consistent with findings from studies such as Leaf et al., (2016) and Lang et al. (2011). ABA interventions can be adaptable to better serve immigrant and culturally diverse families of children with autism. Participants in the current study did not perceive cultural differences as a hindrance to them successfully engaging in the ABA process and benefitting from its positive outcomes. Most participants in the study believed that the tenets of the ABA interventions neither supported nor violated their cultural beliefs and that cultural influences were not significant barriers. Participants in this study appeared to be primarily concerned with achieving positive intervention outcomes, including acquisition of life and social skills pertinent to their child's successful adaptation in society.

This perception supports the claim that culture is not a barrier to successful engagement in interventions, and their positive outcomes. Leaf et al. (2016), reported a similar finding: that ABA interventions are not limited by cultural differences and that they can be adapted to cross-cultural situations. Although this argument holds true in the current study, the challenges and needs identified by participants in this study indicate that immigrant and culturally diverse families of children with autism may experience barriers to successfully engaging in ABA interventions and experiencing positive outcomes if the appropriate service model is not adopted.

The above finding calls attention to the need to adopt an appropriate case management approach that considers the peculiar needs of these families when accessing ABA and other related behavior interventions. Since the ABA intervention does not essentially preclude immigrant and culturally diverse families from benefitting from its positive outcomes, adopting a culturally sensitive and eco-systemic model of service delivery would further expand ABA accessibility to our immigrant and culturally diverse population and further yield positive intervention outcomes. This finding is important for social workers

to be aware of when working with immigrant and culturally diverse families. Social workers are often contracted to work in case management positions where they need to develop behavior intervention plans in addition to other service plans in various domains of clients' needs. Hence, recommendations from this study would assist social workers in making appropriate considerations for needs assessment and intervention plans for immigrant and culturally diverse families of children accessing ABA and other related behavior interventions.

Further, findings from the study reveal that immigrant and culturally diverse families experience accessibility barriers to ABA interventions differently than from their Canadian counterparts. This finding is consistent with findings by Hess, Morrier and Heflin (2008) and Thomas, Ellis, McLaurin, Daniels and Morrissey (2007), noting that immigrant families and culturally diverse families are under-represented in intervention delivery due to barriers to service accessibility. Some of the barriers identified by participants in this study, including delayed diagnosis, lack of familial supports and lack of awareness of autism intervention, are consistent with other findings that have emerged from research such as Sritharan and Koola (2019).

An observation emerging from the data analysis of this study is that most of the barriers identified are largely occasioned by systemic influences such as policy decisions on disability services. Such decisions as funding schemes, age cap on services and referral processes have major influences on the barriers experienced by immigrant families wanting to access to ABA interventions (Taylor, LeBlanc & Nosik, 2018). The policy basis for these barriers were discussed by Dudley and Emery (2014). The authors commented on the influences of politics and science on policy decisions and the implications for service delivery. They argued that autism intervention funding is often targeted towards early learning ABA programs for reasons of its cost effectiveness. They claimed that this funding

paradigm is an interplay of science and politics, whereby scientific evidence base for ABA early intervention is co-opted to justify policy decisions to channel the bulk of funds mainly into early childhood education plans to the exclusion of other ABA programs across the life span. This funding model, arguably a cost effective one, nonetheless results in limited services and resources for middle aged children and older.

Another point is that immigrant children are likely to be disproportionately affected by this funding scheme given the barriers experienced such as a delayed diagnosis for reasons described earlier in this document. This delayed diagnosis results in their ineligibility to access early intervention programs due to age exclusionary criteria. This notion was articulated by participant P1M who, as an immigrant, received a late diagnosis for her child and could barely find any ABA services and had to hire a private behavior tutor.

This frustration was also echoed by participant P3F, who described the service paradigm as regressive, indicating that ABA services and resources appear to decline as children grow older. There seems to be a failure to acknowledge that behavior challenges tend to increase with age, especially as children approach puberty. The frustration borne by this experience motivated participant P3F to venture outside of Canada to the United States to explore available options. Participant P3F reported finding ABA service alternatives both in the private and public sector, where services are ongoing and highly adaptive to the peculiar needs of families. Participant P3F also reported interviewing parents who have had to relocate to the States to be able to access these alternatives. They all reported having better access to ABA services due to their relocation. Participant P3F expressed a wish for a similar service approach to be adopted in Canada, especially in Winnipeg, where service avenues are currently limited, and parents have little say on the nature of services available to their family.

In addition, findings from this study were consistent with findings from other studies showing that successful engagement in ABA intervention processes and the experience of positive outcomes are dependent on certain intervening elements. Findings from this study revealed that the level of parents' awareness, education and employment backgrounds are intervening elements that influence positive parental engagement in ABA intervention process. These findings are consistent with findings from the study by Rivard et al. (2020), where the authors noted that the education and awareness level of participants in their study may have played a significant role in enhancing an understanding and appreciation for the ABA program and intervention process. These authors noted that such findings were contrary to previous arguments that parents may have difficulty in processing and understanding the ABA intervention methods. This finding supports the claim that education and awareness level could mediate the gap in knowledge between ABA service providers and immigrant parents, thus empowering immigrant parents to successfully engage in the ABA intervention process.

The mediating influence of education needs to be further examined given that most studies on this topic have been primarily with middle-class, educated immigrant families that are fluent in English or the language of instruction used for behaviour interventions. This current study did not include participants outside the category of immigrants, but the experience of immigrants with low level education and awareness is barely represented in this field of research. One of the study participants commented that they could imagine that parents with a low-level education would have significant difficulty navigating the ABA intervention process and may be less likely to benefit from the intervention. In fact, all the participants in this study reported that they were able to successfully engage in the behavior intervention process, primarily because of their educational level and employment backgrounds in social sciences. Their reasoning for this claim is that their education and

employment backgrounds in social sciences helped them acquire the knowledge they need to be able to understand the tenets and strategies of the ABA intervention model. It is recommended that future studies in this field consider studying the experiences of immigrant parents with low educational levels engaged in the ABA intervention process. Finding this category of participants, however, could present a significant challenge given that such parents may be less likely to participate in ABA services in the first place due to the identified barriers. They are also likely to have no supportive resources to help them navigate the ABA intervention process.

In addition, some of the service needs and recommendations made by participants are comparable to findings from other studies. Participants' sense of appreciation for a collaborative style of engagement is consistent with findings from the study done by Rivard et al. (2020). In that study, the authors concluded that the partnership and therapeutic alliance between immigrant parents and service providers were major facilitators of a successful parental engagement in the ABA intervention process. This finding raises an awareness for service providers to avoid using a prescriptive style of engagement with immigrant families. Such an approach, as noted by participants in this study, results in the parents feeling as though they lack any strengths and therefore have nothing to offer, and their values and efforts are not recognized. Rivard et al. (2020) further noted that this feeling of invalidation of immigrant parents could make them less willing to share pertinent information that would be useful for intervention planning and implementations. As observed in this study, effective ways of strengthening the alliance between service providers and immigrant families include service providers showing empathy, respect and validation of the feelings and experiences of immigrant families. This practice orientation, as noted by Rivard et al. (2020), requires service providers to demonstrate cultural humility when engaging with immigrant and culturally diverse families.

Adapting elements of the culture of immigrant families such as language is important to facilitate positive engagement of immigrant parents in the intervention process. As noted earlier, this form of inclusion serves to validate the beliefs, values and cultural practices, creating a platform for collaboration between parents and service providers. To note, findings from other research such as Jones and Hoerger (2009), Spector and Charlop (2018) indicated that children who participated in ABA in their indigenous languages evidenced better outcomes than culturally diverse children that took the same intervention in English, which was their second language. This current study did not compare children to determine if findings from Spector and Charlop's study also was consistent with the experience of the participants in this study. However, some participants in this study believed their children would benefit from incorporating their family's cultural values, heritage, and language in ABA intervention delivery process.

An issue of interest, however, is that most participants were ambivalent about cultural influences on ABA delivery process at the initial stage of the interview. Participant P3M for example initially argued that ABA should be culturally neutral with the sole focus on teaching practical and social skills. However, after a deeper reflection on this issue, participant P3M expressed having a new insight on how cultural influences could improve ABA delivery. Similarly, participant P4F held a neutral stance on cultural dimensions on ABA interventions but after further reflections they too, felt that cultural considerations should be a necessary aspect of ABA program delivery to immigrant and culturally diverse families.

This awakening shown by participants raises questions on whether culturally appropriate service is a major need for immigrant families given that participants in this study were initially ambivalent about the significance of cultural influences on the ABA services. Findings from Rivard et al. (2020) gives further insight into this matter. The authors

described the family's perception of the ABA interventions in dimensions that include family priorities, educational priorities, values, and the child's needs. Consistent with this study, the authors described that most participants in their study were primarily concerned with educational priorities such as communication and social skills than other needs such as family and cultural values. The authors believed that the nature of the participant demographics, i.e., being middle class, educated and fluent in the language of instruction, may explain why participants in the study prioritized educational needs over other needs, including cultural needs.

The above finding is consistent with the current study. To note is that the demographics of the participants in this study are like the participants in Rivard et al.'s study (2020). Additionally, participants in this study explained that prioritization of educational needs is because ABA services in Winnipeg are limited, time-bound, and monopolized. There are hurdles to service enrollment and parents are mostly concerned with trying to maximize the most benefits within a noticeably short duration. Accordingly, parents are often not able to fully explore the program in ways that meet their array of needs, including cultural needs and family priorities. This finding calls for a further expansion of opportunities within the ABA delivery model, particularly so that parents could engage in the service process in ways that integrate their various needs, including educational needs, family priorities and cultural values, thus improving the service engagement experience and intervention outcomes.

Conclusion

This study contributes to the insight into the experience of immigrant and culturally diverse families of children with autism accessing ABA and other related behavior interventions. Using a grounded theory approach, the study revealed that immigrant and culturally diverse parents of children with autism experience barriers to successful engagement in the ABA intervention process and optimal intervention outcomes. These barriers are largely structural and multi-systemic. They are the result of policies, funding schemes, attitudes, biases, and competencies of service providers, in addition to immigration challenges and parental psycho-social characteristics. Certain intervening conditions, such as the level of parents' education, socio-economic status, openness, and flexibility shape how immigrant families experience and cope with these challenges and barriers.

The study also revealed that the experience of ABA interventions and outcomes could be further improved by considering the various recommendations highlighted in this study. First is the facilitation of familial supports, access to educational materials and resources, ease of accessibility to interventions, and the dismissal of unrealistic expectations. Service providers need to avoid a prescriptive style of engagement with families and involve the parents in service planning and in the intervention. There should be the inclusion of cultural elements, values, and language services, adopting a life course and transitional approach to service delivery, intensification of life skills acquisition programs, expansion of school-based resources and creating more opportunities, alternatives and platforms for delivery of ABA interventions.

Limitations of the Study

Findings and recommendations from this study must be understood within the limitations of the study. The study participants were few due to the difficulty encountered in recruitment. Due to covid-19 pandemic, finding a diverse pool of participants for the study

was difficult. As in person service was closed, where participants did not attend the centers, disseminating information about the study was difficult as most of the centers had suspended in person services. The demographics of the participants were also not adequately diverse to reflect the experience of immigrants from various ethnicities as participants in this study were mostly of African descent, followed by Caribbean and Philippines. Also, participants in the study were mostly middle-class, educated parents with employment backgrounds in social work and other related social sciences fields.

More so, it is possible that the results of this study may have been different if the pool of participants was more diverse. A more diverse pool of participants would have yielded more information that would have been representative of the diverse cultural backgrounds that immigrant families have. As such, conclusions from this study cannot be generalized to a wider population of immigrants and culturally diverse families of children with autism. Rather, findings from this study can contribute to the developing body of knowledge on their experiences and help to inform policies and intervention planning.

Further, participants in this study prioritized the education and skills acquisition needs of their child over their family's cultural needs. This priority did limit the study as participants spoke more about the barriers that they experience in accessing the ABA program but they did not say much about their cultural needs. This finding was consistent with the study by Rivard et al. (2020) where the authors reported that participants prioritized their child's education needs over their family's cultural needs. Although this priority limits the scope of information that participants shared about the issue of cultural appropriateness of ABA, it does not undermine the benefits that could be obtained from incorporating cultural features into ABA service process, given that participants in the study reported that this model of service make them feel recognized and validated.

Implications for Social Work Education

Findings from this study can help inform the scope and nature of ABA interventions that are taught in social work education programs. Educators can incorporate the recommendations from this study into aspects of social work education that pertain to the delivery of ABA interventions to immigrant and culturally diverse families of children with autism. Incorporating the ideas from this research into social work education will further open avenues for critical engagement of the systemic structures that engender inequitable access to ABA services for minority groups thereby generating dialogues on ways to transform the research findings into actionable plans to facilitate greater access to ABA services and improved outcomes of ABA interventions for immigrant and culturally diverse families of children with autism.

Implications for Social Work Theory and Practice

Considering that social workers are often providing case management services to families, findings from this study would benefit the practice of social work with immigrant and culturally diverse families of children with autism. It is beneficial for social workers to have sufficient awareness of the challenges and needs of immigrant and culturally diverse families of children with autism accessing ABA interventions. This practice orientation requires the adoption of relevant theories, such as eco-systemic theory, in how social workers conceptualize the process of needs assessment, intervention planning and ABA delivery to the target population.

More so, social workers often practice in multidisciplinary settings, where they are having to work with various professionals including occupational therapists, psychologists, and teachers. The recommendations from this study can equip social workers practicing in multidisciplinary settings to engage their multidisciplinary team in developing culturally

appropriate ABA services that would meet the peculiar needs of immigrants and culturally diverse families of children with autism accessing behavior interventions.

Implications for Social Policy

It is evident from this research that policies on the delivery of ABA services need to be reconceptualized considering how the current policies and practices impede access to ABA interventions for immigrant and culturally diverse families of children with autism. Policy change needs to consider the different but interconnected aspects of intervention delivery and family circumstances that affect access to ABA interventions and positive intervention outcomes. In doing so, policy makers need to be mindful of immigrant and culturally diverse families of children with autism that are disparaged from accessing ABA interventions due to systemic barriers such as age limitations, delayed diagnosis, and language barriers.

This awareness raises concerns for a need to redistribute funds for ABA services to cater to the needs of immigrant and culturally diverse families of children with autism. These funds can be channeled into creating more avenues for accessing ABA services to reduce wait times, funding an integrated service process that significantly reduces the bureaucratic and the complicated referral processes such that families can have “a one-stop” service accessibility model from diagnosis to intervention delivery stage. More so, funding can be channeled into expanding the scope of service provisions to deliver life course service model that ensures that the needs of children with autism are met regardless of their ages or stages of development.

Recommendations for Future Research

There is a need to examine the experience of immigrant and culturally diverse parents of children with autism who have lower educational level and are less proficient in English or the language of instruction of mainstream ABA programs. Findings from research, including

Rivard et al. (2020), indicate that this subcategory of immigrant population is difficult to encounter as they are less likely to access ABA services for their children due to socio-cultural barriers. Findings from research about this population would be vital to the general field of research on autism in immigrant communities given that such families would be most likely underserved and underrepresented in program delivery because they encounter more barriers compared to their counterparts with higher socio-economic status.

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Appendixes

Appendix 1: Recruitment Poster

**AUTISM AND THE EXPERIENCES OF IMMIGRANT
AND CULTURALLY DIVERSE FAMILIES**

Accessing Behavioral Interventions

Help us to understand your experiences and challenges with:

- caring for children living with autism;
- accessing interventions for your family;
- enlarging insight into more effective ways of service deliveries;
- Etc.

Please, participate in a 45-minute interview
As gratitude for your participation, we will offer a \$25 gift card.

Research Affiliated with the Faculty of Social Work,
University of Manitoba

Principal Investigator: Adeolu Joseph

Appendix 2: Recruitment Letter

Date: _____

Address: _____

To Whom It May Concern:

RE: RECRUITMENT TO STUDY

I am writing to request your support in helping to recruit participants for a study on the experience of immigrant and culturally diverse families of children with autism accessing Applied Behavior Analysis (ABA) interventions. I am a graduate student in the Master of Social Work program at the University of Manitoba. My research examines the experiences of immigrant and culturally diverse families in Winnipeg accessing ABA interventions for their children with autism. It is anticipated that the knowledge from this study will help improve delivery and outcomes of ABA interventions received by immigrant and culturally diverse families of children with autism. Qualifying participants for the study must be adult parents/caregivers of children with autism aged between 2 and 17. In addition, the children of participants must have been officially diagnosed with autism and must have previously accessed or currently accessing ABA interventions. Participants who elect to engage in this study will be asked to participate in a 45-minute over-the-phone interview.

Information obtained from participants during data collection will be securely locked in the investigator's working space and electronic data will be saved in an encrypted device that is exclusively accessible to the investigator. The saved data will be destroyed after data has been analyzed. Findings from the study will be included in a thesis report that will be completed by the investigator in partial fulfilment of the requirements for completing the Master of Social Work (MSW) program at the University of Manitoba. This thesis report will be publicly presented and made available in the university library. Please, be aware that

identifying information of participants will not be included in the study report to maintain confidentiality.

Participants in the study will contribute to a growing knowledge base on autism issues that have been part of their lived experience. As a token of appreciation for their time, participants will be compensated with a \$25 worth of gift card. Participants also stand to benefit from the safe space and forum that the study will create to allow participants to safely and freely discuss their experiences. One potential risk of participating in the study is that participants may find discussing certain upsetting experiences to be disturbing. A plan is in place to debrief with participants about their experience in the study and to provide them with relevant community resources information to help deal with any emotional concerns that may arise from their participation in the study.

The investigator is requesting your assistance in the recruitment process. Your support is requested to help disseminate information about the study to potential participants that are connected to your agency. The investigator is also requesting that you allow your organisation to serve as a destination for the study posters to be distributed and posted. The investigator is aware of the influence your organization may have on potential participants due to the relationship you share with the potential participants. Please, be aware that participation in the interview must be absolutely free of any undue influence. The decision to participate in the study is voluntary and there will be no penalty for refusing to participate in the study.

Please, kindly advise potential participants to direct their queries or expression of interest in participating in the study to the investigator through the coordinates listed below. Participants who elect to engage in the study will undergo an informed consent process to ensure that they are fully aware and adequately informed about their rights and the

implications of their engagement in the study. Translation resources will also be available to help participants with language barrier to complete the informed consent process and participate successfully in the interview.

Your assistance in this process is highly appreciated. Please, do contact me using my coordinates below should you have any questions or require further information about the study.

Thank you for your consideration and assistance.

Yours Sincerely,

Adeolu JOSEPH

MSW Student,

University of Manitoba

josepha@myunamitoba.ca.

Appendix 3: Recruitment Script

Introduction

- My name is Adeolu Joseph. I am a student in the Master of Social Work program at the University of Manitoba. I would like to invite you to participate in a study to expand knowledge of the experiences of immigrant and culturally diverse families of children living with autism in Winnipeg. The research is affiliated with the University of Manitoba Social Work program.

Aim of Research

- The aim of the study is to understand the experience of immigrant and culturally diverse families of children with autism that have accessed Applied Behavior Analysis (ABA) interventions towards enhancing the delivery of culturally appropriate ABA interventions.
- The study would give participants an avenue to express their feelings and experience of ABA interventions accessible to them and how ABA interventions can be further developed to meet their needs.

Procedure

- During the research, participants would be invited to participate in a 45-minute interview on this topic.
- Participants would be asked about their experiences with accessing ABA interventions.
- Participants' responses would be analyzed, and findings would be communicated in the form of a thesis report.
- Participation in the research is voluntary.

- Families would be gifted a token of \$25 gift card in appreciation of their efforts and time.
- Prior to commencing participation, a formal process of informed consent would be completed with each participant to inform of their rights to participate or withdraw from the study at any point in time.
- Expression of interest would be done by asking participants to sign the consent form.
- The researcher is committed to abiding by research ethics standards, which include that the researcher has a duty to ensure confidentiality of participants' information. To ensure confidentiality, all information collected, hard and electronic copies, would be securely stored.

Anticipated Risk

- A likely risk of participating in this study is that some participants may find discussing the subject about children living with autism to be upsetting.
- However, participants would be assured that the investigator will make available information about relevant resources to help participants deal with any risk or consequences that may have been caused by their involvement in the study.

Researcher contact information:

If interested in participating, please contact the researcher at josepha@myunamitoba.ca.

Faculty of Social Work, University of Manitoba.

Appendix 4: Informed Consent Form

Research Project Title: Autism and the Experiences of Immigrant and Culturally Diverse Families Accessing ABA Interventions

Principal Investigator and Contact Information: Adeolu JOSEPH

Faculty Advisor: David SULLIVAN

This consent form, a copy of which will be left with you for your records and reference, is only a part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more details about something mentioned in the form, or information not included in this form, you should feel free to ask. Please, take the time to read this form carefully and to understand any accompanying information. The investigator will complete the consent process with you over the phone. Prior to reviewing the consent form, the investigator will mail a copy of the consent form (with a prepaid return mail) to your address or send you a copy of the consent form via your email. After reviewing the informed consent form with the investigator over the phone, if you wish to participate in the study, you will be asked to please sign the consent form and return to the investigator either by post mail (using the prepaid return envelope) or by email to the investigator through josepha@myunamitoba.ca.

Purpose of the Research:

The purpose of the research is to contribute to the growing knowledge base on the experience of immigrant/culturally diverse families of children with autism; to aid in advancing the experience and delivery of ABA interventions in a culturally appropriate manner that can adequately meet the needs of immigrant and culturally diverse families of children with autism.

Procedure:

This research will require your participation in a one-time, 45-minute interview with the researcher. The interview will involve semi-structured questions and follow-up questions may be posed during the interview.

Recording of Interview:

The interview will be recorded with the researcher's cell phone and the researcher will be taking notes during the interview for accurate documentation. Please, be aware that you can decline to answer any questions that you do not wish to discuss. There will be no penalty for declining to answer any questions in the interview. Please be assured that your participation in this study will not adversely affect your access to any ABA interventions that you currently receive.

Benefit of Participating:

Insights gained from participating in this study may directly benefit you by helping you become an active participant in knowledge building on ways in which the current available behavioral interventions for autism could be modified to meet the psychosocial and cultural needs of your family.

Risk of Participating:

Conversations during the interview may trigger negative emotions resulting from perceived lack of adequate supports and appropriate interventions. A list of counselling resources would be made available during the interview if you wish to seek counselling or to debrief with a counsellor.

Confidentiality:

For the purpose of data analysis, your demographic information would be collected. The demographic information to be collected will include your name, ethnicity, education level, employment, and length of stay in Canada. To ensure confidentiality, your name will not be included in the study's report. All the information collected (including the demographic information, the consent form, and audio records) will be stored securely in the primary investigator's home workspace. Information collected in hardcopies will be stored in a physical file and locked in a private cabinet in the researcher's home workspace. Only the researcher will have access to the cabinet. Information collected electronically (such as audio recording and email documents) will be stored in a password-protected folder on the researcher's computer. Electronic records of data collected will also be saved in an encrypted USB stick that is only accessible to the researcher as a backup. The USB stick will be securely stored in a locked cabinet in the researcher's home workspace.

Please, be aware of the exception to confidentiality. As per child protection laws in Manitoba, the investigator is required to report any suspected case of child maltreatment divulged during the interview to Child and Family Services.

Honorarium:

To compensate for your time and voluntary participation in this study, a 25-dollar gift card will be given in appreciation. This gift card would be provided right after the consent form is signed and prior to commencing the interview.

Withdrawing from the Research:

Please, be advised that you can withdraw from the research at any point in time before the study's report is submitted to the course instructor. To withdraw from the research, you

need to verbalize your intention to withdraw and/or or send a written statement indicating your interest to withdraw. No questions would be asked about the reason for your decision to withdraw. Your decision to withdraw from the study will not attract any negative consequences.

Debriefing after Data Collection:

Immediately after the interview, you would be asked about your feelings regarding the interview process. You would be asked if there is any assistance or referral services that you may require from the researcher.

Mobilization Plan:

The study findings will be submitted to the researcher's supervisor as part of the requirement for completing the Master of Social Work program. The study findings will be reported in a thesis that will be publicly presented and made available in the university library. Please, be aware that no identifying information of the participants will be included in the study report to ensure confidentiality. Findings from the research may be considered for dissemination to stakeholders such as school divisions and autism intervention centers to help inform policies that can enhance the delivery of culturally appropriate services for immigrant families of children with autism. You would be advised of the anticipated time for the analysis and estimated time for which the report would be completed. You would be asked to indicate if and how you wish to receive a brief 1-3-page summary of the study's result.

Destruction of Data:

Following the submission of study report, data collected during the interview both audiotaped and written notes will be destroyed by Dec. 2020. Electronic data will be deleted from USB device. Hard copy data will be shredded.

Your signature on this form indicates that you have understood to your satisfaction the information regarding participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the researchers, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time, and /or refrain from answering any questions you prefer to omit, without prejudice or consequence. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation. The University of Manitoba may look at your research records to see that the research is being done in a safe and proper way. This research has been approved by the University of Manitoba, Research Ethics Board. If you have any concerns or complaints about this project you may contact any of the above-named persons or the Human Ethics Coordinator at humanethics@umanitoba.ca. A copy of this consent form has been given to you to keep for your records and reference.

Participant's Signature _____ Date _____

Researcher and/or Delegate's Signature _____ Date _____

Appendix 5: Demographic Information

Please, provide your demographic information in the categories below. Be advised that this information is collected solely for the purpose of research analysis to help better understand how your demographic information may contribute to your experience and perception of the Applied Behavior Analysis (ABA) interventions that you have received. Please, know that you are able to decline to provide any of the requested information if you do not feel comfortable to do so.

Name: _____

Age: _____

Gender: Male Female Other (Please, specify): _____

Prefer not to identify

Education: High School Post-Secondary Post-Graduate Others

(Please, specify): _____

Ethnicity: _____

Immigration Status: _____

Household: Single-head household Dual-head household

Employed: Yes No

Length of Stay in Canada: _____

Appendix 6: Interview Questions

- How and when did you become aware of your child's autistic condition?
- How was your experience with getting your child assessed for autism?
- What kind of interventions have you accessed and how was your experience with accessing the intervention?
- Have you previously or are you currently accessing ABA interventions for your child? If so, how was your experience with accessing ABA interventions?
- How was your child's experience of ABA intervention?
- Did you receive training on ABA interventions to use at home to manage your child's behavior? How was your experience with implementing ABA at home with your child?
- What challenges did you experience in the implementation process?
- What supports did you receive to help you with the process?
- What are your values and beliefs about child rearing and development?
- Did you think your beliefs were respected and did this make a difference in your ability to engage in the process?
- What is your overall impression about the outcome of the ABA interventions that you received?
- What did you wish the service providers understood better about your family and ways of living?

Appendix 7: Protocol Approval



**University
of Manitoba**

Research Ethics and Compliance

Human Ethics - Fort Garry
208-194 Dafoe Road
Winnipeg, MB R3T 2N2
T: 204 474 8872
humanethics@umanitoba.ca

PROTOCOL APPROVAL

To: **Adeolu Joseph** (Advisor: **David Sullivan**)
Principal Investigator

From: **Jonathan Marotta, Chair**
Psychology/Sociology Research Ethics Board (PSREB)

Re: **Protocol # P2020:067 (HS24231)**
**Autism and the Experiences of Immigrant and Culturally Diverse
Families Accessing ABA Interventions**

Effective: September 1, 2020

Expiry: September 1, 2021

Psychology/Sociology Research Ethics Board (PSREB) has reviewed and approved the above research. PSREB is constituted and operates in accordance with the current *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans*.

This approval is subject to the following conditions:

- i. Approval is granted for the research and purposes described in the application only.
- ii. Any modification to the research or research materials must be submitted to PSREB for approval before implementation.
- iii. Any deviations to the research or adverse events must be submitted to PSREB as soon as possible.
- iv. This approval is valid for one year only and a Renewal Request must be submitted and approved by the above expiry date.
- v. A Study Closure form must be submitted to PSREB when the research is complete or terminated.
- vi. The University of Manitoba may request to review research documentation from this project to demonstrate compliance with this approved protocol and the University of Manitoba Ethics of Research Involving Humans.

Funded Protocols: Please e-mail a copy of this Approval, identifying the related UM Project Number, to the Research Grants Officer at ResearchGrants@umanitoba.ca

Appendix 8: Autism & Counselling Resource

St. Amant Autism Services

- Offers a 2-year Early Learning Program for pre-school children.
- Enhanced Consultative Services for Families to children and adolescents diagnosed with autism spectrum disorder who have previously participated in the St. Amant Autism Programs.
- Enhanced Consultative Services for Schools to students diagnosed with autism spectrum disorder (ASD) who have previously participated in the St. Amant Autism Programs.

Contact Details

Central Intake (Services) 204-258-7041 / intake@stamant.ca

General Inquiries 204-256-4301 / inquiries@stamant.ca

St. Amant

440 Chemin River Road

Winnipeg, Manitoba

R2M 3Z9

Autism Society of Manitoba

- Promotion of quality of life for people with Autism Spectrum Disorder and their families.
- Connection to activities and resources, and more general information

Contact Details

825 Sherbrook Street, Winnipeg, Manitoba R3A 1M5

Phone: (204) 783-9563

Autistics United Canada – Winnipeg Chapter

- Improving the lives of Autistic Canadians through self-advocacy.

Contact Details

Website: autisticsunitedca.org

Facebook: @ManitobaAutistics

Twitter: @AutisticsUnited

Tumblr: autisticsunitedca@tumblr.com

Community Living Manitoba

- Dedicated to full inclusion of persons of all ages who live with an intellectual disability, through advocacy work under three pillars:
 - family engagement, inclusive education, and inclusive employment.

Contact Details

#6-120 Maryland Street, Winnipeg, MB R3G 1L1

Phone: 204-786-1607

email: aclmb@aclmb.ca

Inclusion Winnipeg

- A registered charity dedicated to making life better for children and adults living with developmental and intellectual disabilities.
- Connecting people, assisting their families to navigate systems and leading the way in advancing their human rights.
- Inclusion Winnipeg provides both advocacy supports and recreational programs.

Contact Details

#1-120 Maryland Street Winnipeg, Manitoba R3G 1L1

Phone: (204) 786-1414

email: info@inclusionwinnipeg.org

Specialized Services for Children and Youth (SSCY)

SSCY The Rehabilitation Centre for Children

- Supports children with special needs in Manitoba and surrounding areas, in reaching their goals and participating in their communities.
- Accessibility services through modifying equipment such as bicycles, swings or chairs to meet the needs of autistic children.

Contact Details:

1155 Notre Dame Avenue, Winnipeg, MB

Phone: (204) 452-4311

SSCY Family Resource Centre

- Family-friendly space to access resources about special needs and general health issues, including books, videos and DVDs about specific disabilities or conditions.
- Take-Out-Toy Services (TOTS) toy lending program provides over 400 toys for use by children with special needs, including electronic, switch-adapted and developmental toys.

Contact Details:

Collette Wilson

SSCY Family Resource Centre Coordinator

Phone: (204) 453-9820

Email: collettew@rccinc.ca

Website: <http://www.sscy.ca/family-resource-centre>

Manitoba Possible

- Provides Occupational Therapy and Physiotherapy services to Children in Winnipeg
- Delivers Speech-Language Pathology Services to children throughout Manitoba.

- Children up to 5 years old receive therapy in their daily environment, such as their home, child-care centre, or nursery school.

Contact Details

Address: 825 Sherbrook Street

Winnipeg, Manitoba, R3A 1M5

Phone: 204-975-3010

H.A.L.E. Autism - Help Autism Live Everywhere

Provides a variety of services to individuals and families living with autism.

- LEGO Social Skills Groups
- Social Skills Groups
- Advocacy
- Computer Software Training
- Continuing Education Classes
- Critical Independent Living Skills for Adults

Contact Details

Please visit Facebook page:

<https://www.facebook.com/haleautism/>

Open Access Resource Centre (OARC)

- Improving the lives of Manitobans with speech challenges using communication devices.

Assisting individuals throughout Manitoba to receive long-term services.

- Provides supports needed for successful implementation of communication devices.

Contact Details

316 Tache Avenue,

Winnipeg, Manitoba, Canada R2H 2A4

Phone: (204)-949-2430

Association for Developmental Autism Programs and Therapies (ADAPT)

Family Support:

- Provides parents with information about relationship-based, developmental programs and therapies, led by trained and certified consultants, for children diagnosed with autism
- Provides information about community services that support the development of children on the autism spectrum and their families
- Create opportunities for parents of children with autism to connect for mutual support

Advocacy:

- Advocates for equitable funding for relationship-based, developmental programs and therapies
- Supports and promotes the expansion of Autism Outreach, Relate, and similar programs, and promote their expansion throughout the school years
- Supports training opportunities for professionals to build and expand on clinical expertise in developmental therapies.

Website Information

<http://www.adaptmanitoba.ca/advocacy-contacts/>

Family Dynamics

- Behavior supports
- Counselling
- In-home family supports
- Parent coach

Contact Details

403-393 Portage Avenue

Winnipeg, Manitoba, R3B 3H6

204-947-1401

Aulneau Renewal Center

- Family therapy
- Play therapy
- Occupational therapy
- Music and expressive arts therapy

Contact Details

228 Hamel Avenue

Winnipeg, Manitoba, R2H 0K6

204-987-7090

Appendix 9: Interview Questions

Interview Questions

- How and when did you become aware of your child's autistic condition?
- How was your experience with getting your child assessed for autism?
- What kind of interventions have you accessed and how was your experience with accessing the intervention?
- How was your child's experience of this intervention?
- Did you receive training on interventions to use at home to manage your child's behavior? How was your experience with implementing these interventions?
- What challenges did you experience in the implementation process?
- What supports did you receive to help you with the process?
- What are your values and beliefs about child rearing and development?
- Did you think your beliefs were respected and did this make a difference in your ability to engage in the process?
- What is your overall impression about the outcome of the interventions that you received?
- What did you wish the service providers understood better about your family and ways of living?