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Fjoralba Xhaferri

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BARRIERS TO HEALTH AND SOCIAL SERVICES UTILIZATION FOR  
IMMIGRANT AUTISTIC CHILDREN IN CANADA

by

FJORALBA XHAFERRI

A master's capstone project submitted to the Graduate Faculty in International Migration Studies  
in partial fulfillment of the requirements for the degree of Master of Arts, The City University of

New York

2020

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This manuscript has been read and accepted for the Graduate Faculty in International Migration Studies in satisfaction of the capstone project requirement for the degree of Master of Arts.

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Date

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Anahi Viladrich  
Capstone Advisor

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Date

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Richard Ocejo  
Executive Officer

THE CITY UNIVERSITY OF NEW YORK

ABSTRACT

BARRIERS TO HEALTH AND SOCIAL SERVICES UTILIZATION FOR  
IMMIGRANT AUTISTIC CHILDREN IN CANADA

by  
FJORALBA XHAFERRI

Advisor: Anahi Viladrich

**Abstract Purpose** – The purpose of this study is to examine the barriers to health and social service access and utilization of Asian and African autistic children and their families in Canada.

**Findings** – The bulk of the literature on autistic immigrant children in Canada has been centered on Asian and African immigrant families. Based on a critical analysis of this body of work, findings helped us to better understand families and children’s specific needs and experiences of care. Limited perceptions of disability, low language skills and limited knowledge of service systems, along with experiences of discrimination and lack of financial means tend to create barriers to health care access among Asian and African families raising an autistic child. Stronger social support systems, including the intervention of a third person (e.g., social service worker, case manager) are needed to help families navigate the Canadian health and social service systems.

**Implications** – Service providers in Canada need to actively work with Asian and African immigrant parents, that have a child with Autism Spectrum Disorder, to help them overcome access barriers to health care and social services. Culturally competent services are needed to improve service delivery and patients’ outcomes both in the short and long run.

**Keywords** – Health and social services, immigration, ethnicity, autism, African and Asian families, barriers, etc.

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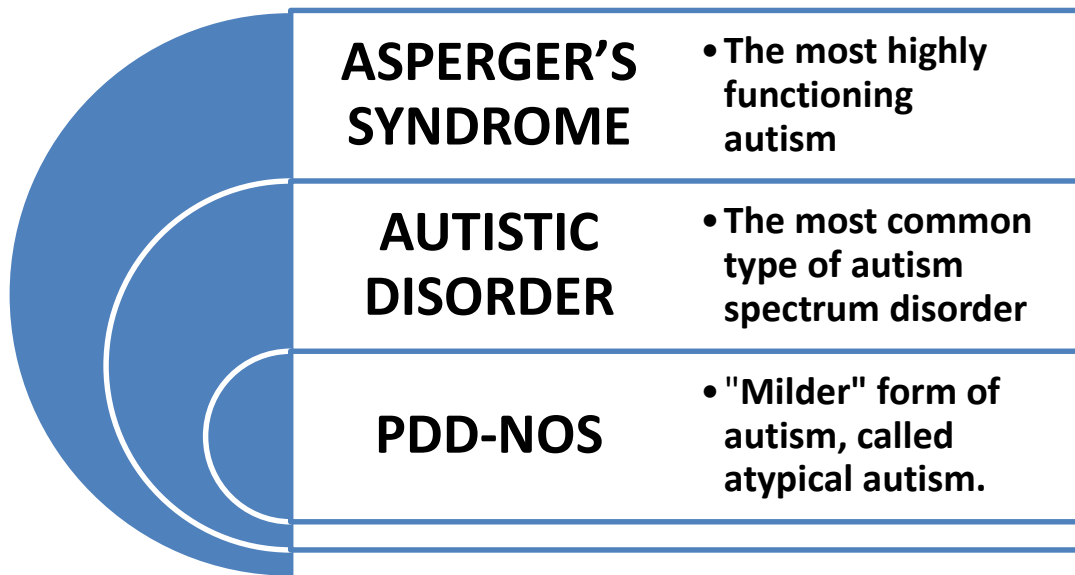
## CHAPTER I

### INTRODUCTION

The objective of the present study is to analyze how autism spectrum disorder is experienced in the context of immigrant families, mostly from Asia and Africa, living in Canada. To that end, this paper will review the literature on the health and social services available to autistic immigrant children in Canada, with special emphasis on the access barriers to health care and the difficulties that they, and their families, experience on a daily basis. The study's specific focus on access and utilization barriers to health care in Canada is aimed to reveal the deficiencies in service provision for Asian and African migrant families with an autistic child.

According to the definition of Sritharan and Koola (2019, 53), Autism Spectrum Disorder (ASD) is a “pervasive neurodevelopmental disorder characterized by social, communication, and behavioral deficits”. ASD is considered a condition that children experience during their first years of age, during which parents play a key role in understanding the signs of the disease, seeking a diagnosis, and pursuing treatment. For parents, diagnosing their children's condition is key in seeking the adequate medical and social services that will eventually help their children improve their medical condition and social adaptation for the rest of their lives (Pondé and Rousseau, 2013).

There exists a general confusion regarding the various types of ailments included under the broader category of Autism Spectrum Disorder. Conditions such as Asperger's Syndrome, Autistic Disorder, Persuasive development Disorder (not otherwise specified, and abbreviated at PDD – NOS) are not being treated separately anymore and, instead, are all put under one category: Autism Spectrum Disorder.



**Figure 1. THREE COMMON TYPES OF AUTISM SPECTRUM DISORDER**

Signs of ASD typically manifest in the early developmental years of a child—regardless of race and ethnicity. Children who have been diagnosed with autism spectrum disorder face difficulties with verbal and nonverbal communication as well as in developing and maintaining stable relationships (Dhanji, 2018). Overall, ASD is considered a lifelong disability that prevents individuals from achieving social and intellectual development and adequate daily living. This condition also results in varied and multiple health care costs to both families and society. In addition to poor social functioning, individuals with ASD are also at an elevated risk for co-morbid psychopathology throughout the lifespan, particularly anxiety and mood disorders (Ratto, 2013).

Parents play an important role in the process of understanding the symptoms of the disability. Effective interventions should consider parents' involvement with the provision of the adequate health and social therapies that will help, in the long run, improve their children's present and future social adaptation (Pondé and Rousseau, 2013).

The purpose of this study is to analyze the literature on immigrant children experiencing autism in Canada, with special emphasis on Asian and African populations. There is an urgent need to learn more about the barriers that immigrant families with an ASD child face in North America generally and in Canada particularly. The scope of this research piece is limited to the child's first years of life, specifically, until the pre-school age (Fellin et. al., 2013).

The following research questions will be explored accordingly:

1. How do immigrant families, and particularly those from Asian and African countries, in Canada, understand and react to their children's Autism Spectrum Disorder?
2. What are the main problems and health access and utilization barriers experienced by immigrant families with an autistic child in Canada, which can lead us to better understand their needs, difficulties, and challenges?
3. What are the main findings from the literature leading to recommendations for future research and intervention?

## **METHODS**

This research is based on a critical analysis of the literature and main research findings concerning the access and utilization of health and social services by immigrant families with ASD children in Canada. The approach is multidisciplinary as it integrates references from the psychological and social sciences literature, as well as a few articles from the medical field.

The inclusion criteria used in this review pertains to the selection of articles that met the following categories: 1. Research literature and scientific studies, 2. Published in English, 3. Published from the late 1980s to today, 4. Focused on two main immigrant communities, Asian and African immigrants, and their families, living in Canada with an ASD child. The articles' selection was achieved in different steps, primarily by giving priority to those focused on ethnicity and barriers to access to health and social services.

## **ETHNICITY, SOCIO-ECONOMIC STATUS AND DISEASE**

In Canada, migration is an integral part of federal policy and, in 2012, immigrants accounted for two-thirds of its population growth (Khanlou et. al., 2017). Canada became the first nation in the world to include specific protection of the rights of individuals with disabilities in its constitution, the Charter of Rights and Freedoms (Grewal, 2010). Although Canada has a reputation of being a nation that takes a positive, human rights approach to public policy, the Canadian federal government does not directly fund treatment programs for individuals with autism regardless of citizenship or legal status (Grewal, 2010).

Ethnicity is a complex issue that can be difficult to define properly. It can be defined as diverse cultural and social dimensions related to race, nationality, culture, religion, language expression and others. When applied to health care, these features can reveal the inequality that some populations experience with regards to access to health care, service utilization and uptake (Bolton et. al., 2013). It is in this context that Jo (2015) insists that beyond generic studies of predictive factors, there have been just a few in-depth population-based studies that consider ASD diagnosis based on children race/ethnicity.

The available evidence does not yet permit a clear identification of the specific causes of ASD. Because of the lack of consensus regarding the etiology of this condition, along with the best course of treatments available, parents in search of answers may develop their own belief systems in relation to their child's diagnosis and potential for improvement. How parents conceptualize the origins of ASD in their child may influence their priorities for treatment, the expectations they may have for health interventions along with their compliance with proposed course of action (Millau et. al., 2018). The social, cultural, and economic adjustment that typically Asians and African immigrant families experience in Canada are added to the difficulties they typically face in dealing with access and utilization barriers to ASD health and social services (Millau et. al., 2016).

For Mangusson et. al. (2012) migration for families with ASD children may involve extremely stressful living circumstances that are linked to cumulative social disadvantages they may experience in the new settlement. On the contrary, Begeer et. al. (2008) affirm that ethnicity and socio-economic status do not consistently influence treatment trajectories, and prevalence of autism, for their ASD children.

An important finding that emerged from this review is the fact that early diagnosis and interventions for cure and treatment involving ASD children can make a significant difference both in their first years of life as well as throughout their life course. Consequently, the sooner immigrant families familiarize themselves with their children's disability, the higher their likelihood of getting the right treatment and the better their children's probabilities of improving their conditions along with their social-linguistic skills through time.

## CHAPTER II

### **BARRIERS TO ACCESS TO HEALTH CARE AND SOCIAL SERVICES FOR ASIAN AND AFRICAN FAMILIES WITH ASD IN CANADA**

In Canada, children with disabilities cope with multiple challenges that include linguistic, social, and economic ones, many of which exceed their specific disabilities (Fontil and Petrakos, 2015). According to Lin et. al (2012) immigrant families with ASD children encounter a unique set of socioeconomic, cultural, and linguistic difficulties that tend to be further exacerbated by barriers to health care access, limited home services, lack of health insurance, and communication challenges when dealing with both medical and social services.

Findings by Khanlou et. al. (2017) show that Asian and African parents in Canada lack much needed social and instrumental support mostly due to language barriers, low income, and transportation issues. Limited services provided to immigrant families by the host community are added to immigrant families' low rates of employment and social marginalization. The literature also shows that African families in Canada lack extended social support networks of relatives and friends able to provide basic instrumental and emotional support to the household. Therefore, immigrant families often feel alone while trying to cope with the potential crisis that may befall when an ASD child needs special care (Kediye, et. al., 2009).

Furthermore, the ways in which immigrant parents understand and approach childhood disability depend on their acculturation levels, knowledge about child development and awareness of the availability of services. These have been found to affect access to health and social services among immigrant families which, in turn, tend to experience social isolation, guilt and shame concerning their ASD children' conditions (Khanlou et. al., 2017). It follows then that parents in

these situations may find it challenging to navigate across service sectors while raising a child who has been diagnosed with ASD.

For the Asians families studied by Sritharan and Koola (2019), barriers to health care access begin with a diagnosis of ASD. The families in their study encountered several difficulties accessing services mostly due to language barriers, low income, transportation limitations, reduced social networks, lower employment rates and marginalization. Other contributing factors were cultural beliefs concerning child development, knowledge about ASD, cultural approaches to disability and awareness of available services. For the parents interviewed, the diagnostic procedure represented a time of mixed emotions as they feared hearing the worst, often felt relief when getting some answers from medical professionals, and hoped to count on a treatment plan that would ameliorate, or even cure, their ASD children's condition.

Rivald et. al. (2019) study reveals that some African and Asian immigrant parents ended up opting for private diagnostic evaluation services due to the excessive delays they encountered dealing with the public health care in Canada. Khanlou et. al. (2017) found delay in diagnosis of ASD children. Furthermore, all immigrant mothers in their study expressed having wanted a confirmed diagnosis of their children's conditions at an earlier age. Therefore, receiving an early diagnosis may help families alleviate stress and better understand and learn about their children's disability. Millau et. al. (2019), interviewed migrant families from Africa, Middle East and China living in Canada. Their study reveals that families' post-diagnosis period was characterized with a range of negative emotions such as sadness, anger, and uncertainty.

A more systematic analysis of the access barriers to health and social services for the Asian and African immigrant families with ASD children, in pre-school age, comes from the research of five different authors and their respective co-authors. They are the following: King et. al. (2011), Sritharan and Koola (2019), Fellin et. al. (2103), Khanlou et. al. (2017) and Rivard et. al. (2019).



Five major themes emerged from their studies as follows: 1. Language barriers, 2. Navigating the system, 3. Financial and economic barriers, 4. Discrimination and culturally care, 5. Support.

## **1. Language barriers**

### **1.1 Translators and translation**

King et al. (2011) found that many of the families interviewed believed that they could have made better decisions regarding their children's treatments had they used a translator when meeting with medical practitioners. The service providers and community organization representatives included in their study mentioned the limited availability of translators on site. A neutral third party—a professional interpreter—was considered necessary to ensure proper interpretation of both words and meaning of phrases. According to a study conducted by Fellin et. al. (2013) some of the main barriers encountered by the immigrant parents interviewed also included access to interpretation services.

Sritharana and Koola (2019) found that immigrant families not only faced interpretation barriers during their encounters with medical practitioners, but also lack of support from their primary care providers and lower satisfaction levels with physician-patient interactions. South Asian mothers, from China, voiced doubts, and concerns regarding the availability of translation services and adequate medical services when needed. One parent stated: “We need more respectful translators with knowledge about disability.” In the study by Khanlou et. al. (2017), research participants also expressed concerns about their providers limited and inadequate awareness regarding the language barriers they experienced when dealing with medical professionals.

### **1.2 Cultural care**

According to King et. al. (2011) communication barriers are not only due to the differences in the languages spoken, but also to the cultural meaning attached to words and terms. Their study

suggests a need for translation and interpretation services along with competent cultural skills that take into consideration the varied cultural meaning of verbal expressions. Fellin et. al. (2013) conducted research on language facilitators that rely on culturally sensitive care toward enhancing immigrant families' positive experiences. Culturally sensitive care reflects an eco-cultural approach to treatment planning that considers the family's social and physical environment and includes the support systems available to the family and child, along with interpreting the family's cultural values and beliefs concerning treatment options. This model also relies on immigrant parents' access to resources and the availability of health care professionals who are sensitive to their beliefs, values, and worldviews.

Sritharana and Koola (2019) found that differences in cultural understanding of ASD among immigrant families from Asia and Africa need to be taken into consideration when making key decisions about ASD children. For instance, among certain cultures children's lack of eye contact—a typical condition among ASD individuals—may not be identified as a social difficulty and thus may further delay immigrants' help-seeking behaviors on behalf of their offspring. Recent immigrants may be placed at a disadvantage concerning finding appropriate medical care and support for their ASD children, as they enter health care settings framed by institutional constructs that are incongruous with their ethnic perspectives (Sritharana and Koola, 2019). Failure to acknowledge immigrants' cultural beliefs regarding autism can lead to health care professionals being dismissive regarding alternative treatments sought by immigrant parents on behalf of their ASD children.

Health care providers should make an effort to understand immigrant families' knowledge and experience with autistic disorders toward forging meaningful therapeutic alliances, which will eventually involve a hybrid approach in successfully addressing ASD children's needs (Sritharana and Koola, 2019). In fact, it is possible to seek alternative therapy options and integrate cultural-based therapies which, together, will lead to better outcomes for ASD children. The ultimate

treatment goal should be based on providing culturally sensitive approaches to immigrant families with ASD children in order to decrease their fear and apprehension to health service provision, while helping them gain better medical access and achieve early intervention on behalf of their children.

In sum, it is crucial for health care professionals to be aware—and respectful—of immigrants’ cultural beliefs concerning health and disease models generally and autism particularly. Additional research is needed to identify how such beliefs may impact the family and ASD child in both negative and positive ways.

### 1.3 Language barriers

King et. al. (2011) study showed that participants agreed with medical providers’ decisions on behalf of their children’s treatments even if they were not comfortable with them. This was the case when parents did not feel entitled to voice their concerns regarding their ASD children’s health care needs nor were able to request alternative treatment options. Other times, parents hesitated to accept services because they did not understand what was being offered to them. Fellin et. al. (2013) found that language barriers can lead Asian and African families to make uninformed decisions about medical treatments. Parents in their study found it difficult to understand the specialized language used during the medical encounter. Their findings also highlight the fact that parents did not have previous knowledge about their ASD children’ disabilities.

For instance, some parents were hesitant about complying with their child’s medical treatment because they did not understand the services being offered. An Asian parent in King et. al. (2011) study challenged the doctor’s recommendations to contact palliative care when her child became ill because of language barriers: “I didn’t know what that meant” he replied. These results suggest that translators and interpretation services should be provided even when English proficiency is assumed. In this vein, Khanlou et. al. (2017) add that communication barriers—that keep

immigrants from understanding medical terminologies—may further aggravate Asian and African parents' frustrations. For instance, many mothers in their study did not understand the meaning of “respite care” and therefore, were not able to request these services for their children even when they were available to them.

Despite the fact that much more research is needed in terms of improving treatment for ASD children, Sritharana and Koola (2019) argue that, in Canada, some health programs and organizations have been successful in offering multi-language health materials and adequate interpreter services, along with culturally specific services in diagnosis and intervention. However, as reported by most findings, and even when services exist, immigrant families may not actually have access to them.

## **2. Navigating the System**

### **2.1 Difficulties searching for services**

King et. al. (2011) found that one of the major barriers for immigrant Asian and African families in Canada is lack of knowledge about how to seek and find appropriated health care. For immigrant families, finding a family doctor able to treat their ASD children may be difficult and often leads to delay in getting specialized treatment. Families may not know how to access primary care services or may ignore the role of family doctors as key figures in providing entry into the medical system. Fellin et. al. (2013) calls this situation “service systems issue” due to the limited information available for immigrant families in relation to the services specifically tailored to them. For Sritharana and Koola (2019) the process for Asian and African immigrant parents is further complicated by the unique challenges they face in effectively accessing health services and in navigating the system at the community level— where services are not always easily accessible.

Khanlou et. al. (2017) shows how African mothers in their study encountered several obstacles in trying to access services due to lack of information which, in turn, delayed their

children's entry into the health service system. An African mother expressed her concern in these words: "We have to do all search about our ASD children services by ourselves. Lots of work."

Rivald et. al. (2019) reports the lack of centralized information sources available to immigrant families. Such information system should provide an entry point for parents seeking diagnosis services on behalf of their children and, ultimately, gain access to timely and adequate treatments. The African and Asian parents interviewed in their study explained that the health and social services systems available to them were difficult to understand. One father actually stated: "we don't understand everything, uh, we always have difficulty making a medical appointment even though we now have physicians and we are still learning about the network but we do not know it well enough."

## 2.2 Lack of knowledge of services and barriers to access

Most of the interviewees in King et. al. (2011)'s study lacked knowledge about the specific services available for their disabled kids. Just providing information to parents may not be enough if they do not know what the information means. Another important issue is that newcomers in Canada may be in the process of learning about the available health and social service agencies, including on how to get services through informal channels. Khanlou et. al. (2017) concluded that access to health programs geared to ASD children is often difficult since the application process is time consuming and often entails joining waiting lists before families can utilize them. Most immigrant mothers expressed their frustration with the long waiting times for accessing services and, more importantly, for not knowing when their child's turn would come. They also reported that, when they finally received medical services, it was sometimes too late. In other cases, the services' potential benefits—as in the case of speech therapy—were diminished by the fact that their children got them at an older age. In other occasions, families received the phone calls from the health and social services agencies

when they were away from home. In those cases, they missed the opportunity to accept the treatment offered and were asked to re-register into the system, which meant joining endless waiting lists.

In sum, the reviewed literature shows that immigrant parents, and particularly mothers, are often discouraged from seeking health services on behalf of their ASD children due to complicated bureaucratic process, such as the completion of long application forms that are difficult to understand. Lastly, excessive paperwork was also identified as a major barrier in accessing services.

### 2.3 Perceptions of care and the health system

Immigrant families tend to not discuss their fears concerning their ASD children's conditions due to an overall respect toward medical authority. Authors tend to point out that most immigrant families came to Canada from countries where the medical authority is highly respected and not usually questioned. Furthermore, Asian and African immigrant families may not be used to a family-centered health care system and may view the primary doctor as the sole expert (King et. al., 2011). One of the Asian mothers interviewed reported that her input concerning the treatment options for her child was not needed due to the fact that she had total faith in the Canadian medical system. Despite of being uncomfortable with the idea of her ASD child having surgery, another immigrant mother allowed it based on her total respect for the doctor's expertise. Furthermore, many African and Asian families felt that they should accept the medical and social services given to them as these were considered a privilege in the first place.

To the scenario described above, Fellin et. al. (2013) noted that African and Asian parents are often unaware of the extent of the possibilities for their children's independence along with their achievement of personal goals. These authors call this situation as "divergent perspectives of disabilities and health care systems". Khanlou et. al. (2017) added that immigrant families usually face several challenges when trying to learn how to navigate the social and health service sectors in Canada. In this line, families from East Asia and Sub-Saharan Africa may not know about the

possibilities for a cure for their ASD children and about their ability to reach their own goals. Similar to the findings by King et. al (2011), Khanlou et. al. (2015) report that one of the parents interviewed agreed to surgery for his/her son, because of the belief that the doctors were the experts, even though she was uncomfortable with it.

Overall, the literature suggests that immigrant families may not discuss their fears with doctors nor explore their children's treatment options. In sum, health care providers need to ask specific questions, along with building trusty relations with immigrant parents, for the latter to feel comfortable to raise questions about treatment decisions.

### **3. Financial and Economic Barriers**

#### **3.1 Funding for equipment and services**

According to King et. al. (2011) African and Asian immigrant families tend to struggle due to their limited income and social resources, which may eventually keep them from accessing the medical and social services that their ASD children need. Health care providers could help their clients become aware of the funding sources available for services for their children.

Similarly, the South Asian parents interviewed by Sritharana and Koola (2019) mentioned the need for customized smartphone apps to promote information and available resources for the purpose of raising awareness about their children's mental health. South Asian parents see this as a way to deliver educational resources to their underserved immigrant community in order to mitigate the stress these parents feel when not informed about their children' ASD disability. Khanlou et. al. (2017) study underlines parents' inability to bear the financial costs of many of the tests and services that, albeit not covered by the Canadian government, were required for their children's proper diagnosis and treatment.

As a final note, it is important to point out that there are many free programs and funding available for immigrant families raising an autistic child in Canada regardless of their legal status, financial means, and availability to pay. Closer collaborations between social and health service agencies and Asian and African community members is needed. Parents should receive the proper information, and logistic support, leading to ASD children's access and utilization of state and local level services.

#### **4. Discrimination and culturally appropriate care**

##### **4.1. Discrimination**

From the analysis of the literature in Canada, fear of discrimination is a significant concern among immigrant families with an ASD child. In this line, King et. al. (2011) found that language barriers often lead to open and subtle discrimination by health and social services agencies. For instance, service providers may not be patient with families that struggle with language issues when trying to express themselves in English. Fellin et. al. (2013) found that Asian families fear the possibility of experiencing discrimination and/or cultural miscommunication when dealing with Canadian health and social service agencies. One of the parents interviewed in their study suggested the following: “there could be a misunderstanding, like, you don't know the culture, you don't know the language, and you don't know the customs. So, there is hesitancy in both the immigrant part and the native part too, you do not know if what you are doing is right or wrong.”

From the analysis of the readings, it transpires that immigrant families do not feel comfortable expressing their cultural and linguistic needs when approaching and dealing with health and social service agencies in Canada. This may cause parents' hesitation to seek key medical services, with a correlated negative impact on the health of their ASD children.



#### 4.2. Perceptions and knowledge of disability in migrant families

In King et. al. (2011) study, one Asian mother stated that she believed that it was God's will that her son had a disability. Another Asian family believed that Western treatments are not enough to make their child become "normal." From the perspective of service providers, there is no clear distinction between being "sick" or being "disabled" among many immigrant families. A community service representative also affirmed that many immigrants see the disability as an illness.

Fellin et. al. (2013) asked African parents if they felt happy upon realizing the possibilities available to their children— meaning that they had accepted their disability. One of the parents stated the following: "Back in my country kids that have some issue with disabilities just sit on the corner and wait for things to happen for them." Parents interviewed by Fellin et. al. (2013) had perceptions of autism as an "illness" with no possible treatments. They thought their autistic children would be marginalized with no possibilities to cure and integrate them into mainstream society.

Rivald et. al. (2019), found different meanings in the cultural understanding of autism and disability among the immigrant families interviewed. For instance, an Asian mother explained that in her country a child with autism would often be consider "retarded," whereas another mother said that there is a general idea that autism exists but is not known under this label. An African mother interviewed affirmed the following: "we say the child is handicapped, that is all." Families' understanding of autism as a condition of being retarded and handicapped may influence the time and modality they search for services on their children's behalf. If parents realize that autism is not a totally incurable disability, and learn for the benefits of the early interventions, ASD children may have access to treatment services that will eventually make a difference in their lives. Through time, they may have a higher probability to be integrated in mainstream society and have a normal life for as much as it is possible.

#### 4.3. Gender and family roles with disable individuals

Understanding gender relations is pivotal when dealing with Asian and African immigrant families. In King et al. (2011) study, one African mother suggested that among Muslim families it is up to the men to make all important decisions, not the women. Husbands are also expected to ask all relevant questions and receive all key information from medical providers regarding their families' wellness and medical issues. Service providers also acknowledged that newcomer autistic children are not often involved in decision making processes and outcomes—something that seems contrary to the family-centered care principles that guide the service provision for autistic children in Canada.

Khanlou et. al (2017) found that their interviewees reported different level of daily stress particularly when trying to balance their personal and work life. Not only did some fathers feel responsible for seeking health information on behalf of their ASD children, but they also experienced pressure to balance family, work and routine daily tasks which, together, led to different forms of personal and family tensions. Fears of losing employment and financial support create worry and guilt for fathers when it comes to taking care of their ASD children's medical treatment. Furthermore, as noted in the literature analyzed here, after migrating to Canada, Asian and African mothers tend to challenge traditional gender roles mostly by becoming employed and earning money (King et. al., 2011). Often, this creates tensions as fathers tend to feel stigmatized within their communities and being viewed as not as strong and dominant in their family units as they used to, and should be. Nevertheless, the more the fathers get informed with their children's disability, and possibilities for a better life through treatment, the better the household environment becomes in the long run.

## **5. Support**

### **5.1 Social and Community Networks**

Social support has been recognized as an important positive influence on the health and wellbeing of immigrant families, which is key in reducing family burden for parents of children with disabilities. Counting on adequate social support has been linked to the timeliness and effectiveness in outcomes of ASD interventions (Khanlou et. al. 2017; Dhanji, 2018). Both perceived and actual social support have been reported as essential in reducing parental stress, increasing coping skills, and preventing parents from developing mental health conditions such as depression and anxiety.

The reviewed literature agrees on the lack of social and community support available to immigrant families with ASD children in Canada (Khanlou et. al., 2017; King et. al. 2011; Sritharana and Koola, 2019). King et. al. (2011) found that most of the Asian and African mothers interviewed in their study voiced a need for additional support along with fears for being the main, and usually only, caregivers of their ASD children. A female interviewee, for example, stated that immigrant mothers should support each other—and receive support from other parents—to exchange key information about health and community resource in order for their children to have the best life possible. In their study, Khanlou et. al. (2017) found that mothers often reported feeling socially isolated because of the time invested in dealing with their ASD children, which in turn prevented them from having free time to meet with friends and seek additional assistance.

A way to improve the support received by Asian and African families in Canada, would be to promote their engagement with the local communities in the cities they reside. Churches, schools, recreational centers, and community events can create a network of families with autistic children. In this way, parents would be able to share and exchange necessary information with one another, particularly regarding the health and social services available to their ASD children (Sritharana and Koola, 2019).

## CHAPTER III

### DISCUSSION

According to Millau et. al. (2018), the way in which immigrant parents conceptualize the origins of Autism Spectrum Disorder may influence their priorities for treatment, their expectations regarding treatment interventions as well as their compliance with the proposed treatments. The literature shows that immigrant parents' perceptions of disability influence their health care use, which correlates with families' willingness to seek services as well as shapes the views they have regarding their child's needs and possibilities (King et. al., 2011; Fellin et. al., 2013; Rivard et. al., 2019).

From the perspective of service providers, studies show that most newcomer families from Asia and Africa do not know that their child disability can be improved and change significantly, with the appropriate health and social interventions received at an early state. Many immigrant parents believe that their ASD children are permanently "sick," with no possibilities for improvement.

King et. al. (2011) show that recent newcomers (5 or less years in Canada) reported having more positive perceptions of the care their child receive than did older residents (6 to 10 years in Canada), no matter their initial doubts for their children' improved outcomes in the long run. Therefore, it seems that it is only with the passing of time that parents may begin to perceive the barriers to services. This may be because their expectations rise along with their further integration into the host country.

The findings discussed in this review suggest that most immigrant families believe that they would have been able to make better decisions regarding their children's treatment had they had a translator when meetings with their children's doctors. Lack of translation services lead immigrant

parents to often decline services because of lack of understanding of the actual meaning of doctors' recommended treatment. In fact, immigrant parents agree with medical recommendations even though they do not completely understand them (King et. al., 2011; Fellin et. al., 2013; Sritharan and Koola, 2019). As stated in this paper, language barriers do not allow immigrant parents to communicate their concerns about treatments nor ask for alternative medical treatment options. As discussed earlier, barriers in communication not only do exist because of the language spoken, but also due to the diverse cultural meaning attached to words and terms.

The literature has also shown that financial difficulties, regardless of immigration status, affect access to services and support systems (King et. al, 2011; Felin et. al., 2013; Khanlou et. al., 2017). Lack of resources may delay access and utilization of the services needed. Some of the parents interviewed by Fellin et. al. (2013) perceived the health care system and doctors as respected authorities, which prevented them from asking questions or probing for more information. Divergent perspectives about service provider and client relations also led parents to agree to recommendations that they did not fully understand or were not comfortable with.

Contrary to the family-centered care principles that guide the service provision available for autistic children in Canada, the literature points out that ASD immigrant children tend not to be involved with their medical treatments (Khanlou et. al 2017; King et. al., 2011). For instance, ASD are not often aware of the available health and social services that can help them improve their everyday skills and abilities. Rivald et. al. (2019) notes the lack of a centralized information concerning the available medical treatments to ASD immigrant children., which are key in assisting parents to obtain a diagnosis for their child and, ultimately, gain access to effective treatment and intervention services.

## **LIMITATIONS AND RECOMMENDATIONS FOR FUTURE RESEARCH**

As discussed in this paper, there is limited data on the appropriate services provided to immigrant families with children suffering of ASD in Canada. Fellin et. al (2013) and King et. al. (2011) point out to the urgent need for ethno-specific research on Asian and African immigrants' cultural beliefs regarding health-seeking beliefs and practices. Papoudi et. al. (2020) note the existence of significant gaps in understanding how different cultures and belief systems influence the unique health and educational needs of ASD children. As shown by Rivald et. al. (2019) minority ethnic populations are underrepresented in research studies on autism. Therefore, and in tune with the authors reviewed in this paper, there is a need for in-depth studies on the influence of cultural and ethnic factors that determine disease perception, health-seeking behavior and service satisfaction among Asian and African immigrants living in Canada.

More research is also needed to better understand health care access and challenges to service provision experienced by Asian and African autistic children living in Canada. We also need more studies on how parents conceptualize their children's disability—a crucial issue in determining the health-seeking process on behalf of their children. As discussed in this paper, counting on a translator seems to be pivotal in parents' ability to make better decisions regarding their ASD children's course of treatment. Barriers in communication are not only based on the language spoken, but also on the complex cultural meaning attached to everyday words and medical terms. The fact that Asian and African parents tend to perceive the health care system generally and doctors particularly as authority figures, often prevents them from either asking questions or requiring more information about their children's medical conditions.

Ethnic minority children are at risk for misdiagnosis and under diagnosis. In this line, a key issue identified in the literature pertains to the lack of early health interventions targeting Asian and

African autistic children in Canada. Early screening and diagnosis should be considered a priority in these children's health treatment.

Language support should be explicitly offered to immigrant families and it should not be assumed that those families know that such support exists. It would also be beneficial for health and service providers to be trained on how to work with translators (King et. al., 2011). Hiring service providers from diverse cultural and ethnic backgrounds could help break down barriers between Asian and African immigrant families and service providers.

The literature reviewed in this study shows how cultural views of ASD is dependent on what is considered as socially normal or abnormal among Asian and African families. Any recommendations to yield more culturally sensitive practices must consider what organizations can realistically achieve in terms of their available services, staff training, and institutional adjustments to existing and novel practices.

Gender relations should also be taken into consideration when dealing with Asia and African families in Canada. As discussed in this review, gender dynamics need to be considered including interpersonal expectations (based on who the primary caregivers and decision-makers are within each family) along with parents' preferences for matching the gender of the child with that of the service provider. As reviewed in the literature, when Asian and African parents talk about their children, not only do they describe their beliefs about ASD but also their experiences of pain and suffering including on how profoundly their children's health condition has impacted their lives and changed their families.

To enhance social support for families with children with ASD, a third person should be available to help them navigate the health system, find the appropriate services, assist them filling out forms, get additional help, etc. The role of a third person is pivotal (as part of the family support system) in improving success in both service outreach and in empowering the family toward

requesting and using, the services needed. Public health advocates should become aware that immigrant parents usually feel overwhelmed and are under-informed when it comes to accessing key health and social services.

Coaching programs offered to Asian and African families of ASD children would benefit from the inclusion of members of the extended family. This would help enhance the amount and quality of instrumental and emotional support that parents and their children receive. Finally, group-based information programs tend to provide immigrant families with opportunities to join and develop social support networks in the host country.

## **CONCLUSIONS**

The present study identified some of the main barriers encountered by immigrant families, mostly from Asian and African origin, with an ASD child in Canada. They all shared a common experience of having immigrated to Canada and facing a system of health and social services that differs from the ones in their native countries. As discussed in this paper, perception of disability, language barriers, financial difficulties and lack of appropriate support systems seem to be key determinants of access to effective health and social services for Asian and African families raising an ASD child in Canada (Sritharan and Koola, 2019; Fellin et. al., 2013; Rivard et. al., 2019).

In order to provide culturally sensitive care, service providers should be mindful of the gender roles played in the child's family, including the distribution of care-taking responsibilities. Caring for children with developmental disabilities can be emotionally and mentally exhausting for immigrant families. Therefore, formal support systems should include a third person able to help families navigate the health and social services available to them. It is also imperative to understand, and address, the challenges faced by immigrant families to ensure that they do not end up being marginalized by health and social service agencies in the host society (Sritharan and Koola, 2019).



Professional organizations such as the American Psychological Association (APA) have been increasingly calling attention to the need to account, in both research and professional practice, for linguistic and cultural differences among the immigrant populations they treat (Rivard, et. al., 2019). The existence and availability of health and social services for immigrant families does not necessarily mean or guarantee that they will access and use them. Furthermore, prevention efforts should include informing parents about the social support systems and services available to them.

Specific policies and guidelines should be further developed to improve both access to medical treatments and the quality of service provision. Some of the areas that still need to be developed include: increasing availability of multi-language materials, providing adequate interpreter services, promoting culture-specific awareness programs focused on the importance of early diagnosis and intervention, and improving knowledge about the Canadian disability accommodation rights/laws for immigrant families. Future work on these areas may radically change the pathway to diagnosis and treatment for Asian and African autistic children and, in the end, may improve health equity. The prevalence of autism among Asian and African families has risen sharply, so has its visibility (Khanlou et. al., 2017). Consequently, the role of parental and community resources for early identification and intervention for children with ASD has somehow improved in recent years.

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