Research Report

VOICES OF IMMIGRANT MOTHERS OF CHILDREN WITH DISABILITIES: AVAILABILITY AND USE OF SOCIAL SUPPORT

Nazilla Khanlou, Nasim Haque, Deborah Davidson and Mahdieh Dastjerdi

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Availability and Use of Social Support

by

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Acknowledgements

Nazilla Khanlou
Principal Investigator – Mothers Project

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Executive Summary

Toronto and the GTA have undergone a significant demographic transformation over the last three decades. Today, almost half the population of Toronto was not born in Canada, and a large and growing number of those come from non-European countries (Statistics Canada, 2015; Toronto, 2013). With immigration now accounting for two-thirds of Canada's population growth and the majority of those settling in large urban areas like Toronto and the Greater Toronto Area, the process of transformation can be expected to continue and evolve toward ever increasing diversity of language, religion, ethnicity and culture (Statistics Canada, 2015).

While Toronto has undergone and is undergoing a process of population change, it is not clear that our institutions, programs and services are adapting to the demographic shifts in diversity. Asking how well human service systems are responding to demographic shifts is a vital question with regard to immigrant mothers of children with disabilities. Research tells us mothers of children with disabilities experience higher rates of poor physical and mental health (Statistics Canada, 2008c). It further suggests one critical factor explaining poor health is the lack of adequate services and supports (Gagnon et al., 2013). The intersection of migrant status and mothering a child with a disability or disabilities intuitively suggests an amplified risk to the health of immigrant mothers due to factors such as English as second language, cultural differences, and inadequate health and social systems knowledge. Despite this potential for heightened risk, less well understood is how equitable the availability and accessibility of services and supports are for immigrant mothers of children with developmental disabilities. Ultimately, the current lack of research on access and availability represents a significant knowledge gap.

This report describes the findings of a qualitative descriptive study to begin to fill the knowledge gap by exploring the questions: how well are services and supports responding to the challenges faced by immigrant mothers of children with disabilities, and how well are immigrant women coping? By talking to immigrant mothers, the study seeks to learn about the enabling factors for social support as well the challenges they face on a day-to-day basis. By hearing the voices of immigrant mothers, the purpose is to provide information and direction that helps in understanding what is needed to protect the health of immigrant mothers as well as promote access to a service system that facilitates the optimal growth and development of their children with developmental disabilities.

A total of 57 participants from the Greater Toronto Area (GTA) participated in the study: thirty immigrant mothers of children with disabilities from diverse backgrounds and twenty-seven service providers representing a range of service organizations serving immigrant families. Semi-structured individual telephone interviews were conducted, and all participants had the option to withdraw from the interview or refuse to answer any question at any stage of the interview.

Participants in our study identified many challenges faced by them in accessing social support for themselves and their families. Challenges included: difficulty in navigating the system, lack of

relevant information regarding services, excessive paper work mandated by organizations for access to supports and services, dispersed services, transportation problems, lengthy waiting time, cost of services and lack of respite care. Many mothers specifically mentioned the challenges they faced in receiving needed services in a timely manner, and some expressed experiences of discrimination by service providers. Mothers pointed out that taking care of children with disabilities is a long term commitment and without the needed support services mothers are under constant tension, ongoing fatigue, and emotional stress due to concerns about their children's education, health and wellbeing with very few resources at hand. Many service providers agreed with the challenges described by mothers; however, language barriers and cultural issues were emphasized by service providers as additional challenges when dealing with immigrant families. Despite the challenges brought about by an at-times inhospitable service system, mothers generally expressed that caring for their children with disabilities was both "joyful and satisfying". Service providers recognized the commitment of the mothers towards getting support for their children.

Our recommendations are categorized by three tiers of social support – structural, instrumental and emotional – and further distinguished by the system levels of macro (policy and institutions), meso (services, schools) and micro (support for friends and family) (House, 1981; Brofenbrenner, 1986).

Structural support (Macro): the public policies and practices of social systems and institutions that help establish an overall supportive living environment.

1. Improve access to services – Use best practices to Introduce Key Workers or Case Managers in the system.
2. Improve service by enhancing staff knowledge and skills through pre- and in-service training of all service providers, with emphasis on the importance of understanding the unique needs of families across cultures.
3. Ensure adequate provincial funding is provided for effective delivery of social services either through government funds or through expansion of health and social insurance policies. However, to ensure equitable access of services, special funding allocations must be in place for disadvantaged and economically poor populations (e.g. children with disabilities within immigrant families).
4. Improve inter- and cross-sectoral service coordination through appropriate legislation.
5. Improve coordination between immigration and child welfare authorities so that immigrant mothers do not fall through gaps in law and policies in these two domains.

Instrumental support (Meso): the provision of financial assistance, material goods, or services.

6. Implement programs to raise public awareness and decrease stigma against children with disabilities.
7. Help empower immigrant mothers with children with disabilities and to have social support programs informed by their lived experiences, actively involve mothers in the process of planning, program implementation and governance.

Emotional support (Micro): the concern and attention provided by family, friends, professionals and others.

8. Ensure availability of respite care for mothers of children with disabilities to give them temporary relief and ease their daily caregiving burden.
9. Incorporate evaluation of services given to mothers to assess whether they find them helpful to them and their families.

Policy Implications

The wide-ranging nature of challenges referred to by study participants draw attention to the impact that inadequacies in the current support systems have on the lives of mothers of children with disabilities and their families. Presently, services do not adequately fulfill the needs of new immigrant mothers. A key reason for this could be the lack of family-centred and timely service availability. This in turn may lead to poor access to health care, school services and other required social services, resulting in increased stress and 'extra-ordinary' demands associated with mothering children with disabilities.

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1.0   Introduction

The United Nations Convention on the Rights of the Child states that all children with mental or physical disabilities should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community (United Nations, 1989).

As a signatory to the United Nations Convention on the Rights of the Child and the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD),Canada has a positive obligation to work towards meeting the human right aspirations for children with disabilities (Government of Ontario, 2012). However, in the Canadian context, policy pertaining to children with disabilities is not well researched (Peter et al., 2007) and although children, as a group, have been named as a priority in governmental agendas, the reality is that children with disabilities are not always considered (Prince, 2002, 2004).

"Children with disabilities should not be treated or regarded simply as the recipients of charity. They have the same rights as others – among these, the right to life and to the opportunities that flow from good health care, nutrition and education, the right to express their views and participate in making decisions, and the right to enjoy equal protection under the law. They belong at the centre of efforts to build inclusive and equitable societies – not only as beneficiaries, but as agents of change. After all, who is in a better position to comprehend their needs and evaluate the response." (UNICEF, 2013)

The *International Classification of Functioning, Disability and Health* (ICF), defines disability as an umbrella term for impairments, activity limitations, and participation restrictions. According to the ICF, disability is represented by the negative aspects of the interaction between individuals with a health condition and their personal and environmental contexts (such as negative attitudes, inaccessible transportation and public buildings, and limited social supports) (WHO, 2011). The recognition of the role of social and physical barriers in disability has supported the transition from an individual, medical perspective to a "social model". The social model reflects the idea that 'disability' is a social construction involving an interaction of the person and their community or society (WHO, 2011). As well, the ICF definition reflects a move toward the identification of 'participation' as an important dimension of health and takes into account the key social determinants that influence population health.

Children with disabilities and their care-giving mothers are among Canada's most vulnerable. Across Canada, 174,810 (4.6%) children between the ages of 5 and 14, and 27,540 (1.7%) children under the age of five have one or more disabilities (Human Resources and Skills Development Canada, 2006). In Canada, approximately 96% of care for children with disabilities is provided by their mothers (Yantzi & Rosenberg, 2008). The findings from the Canadian National Longitudinal Survey of Children and Youth observed that mothers of children with disabilities were twice as likely to report

being in "poor" or "fair" health than those without children with disabilities. There was no observed difference among fathers of these children (Statistics Canada, 2008b). These findings are similar to the findings of another study conducted in Europe: mothers of children with autism, physical and intellectual disabilities or Asperger's syndrome report higher levels of stress and depression and a higher incidence of seeking professional help and taking medication (WHO, 2010). Overall, there is good evidence that the caring role of mothers for children with disabilities can be a risk to health.

> *"Research on child disability is woefully inadequate. The resulting lack of evidence hinders good policy making and service delivery for children who are among the most vulnerable" (UNICEF, 2013).*

Less well understood is the prevalence of disabilities among children within immigrant families or the needs of their care giving mothers. The summary impact of this lack of knowledge and understanding is a lack of priority and response from policy makers and program planners alike. And the significance of the knowledge gap is growing as Toronto, the Greater Toronto Area (GTA) and much of Canada is increasingly diverse in population. With almost half of the Toronto's residents being foreign-born and two thirds of population growth being driven by immigration (Statistics Canada, 2013), there is a pressing need to close the gap and create meaningful changes in both policy and practice.

In an attempt to fill the gap and encourage policy and service system responses, this qualitative study was conducted in the Greater Toronto Area (GTA) to seek out and listen to the voices of immigrant mothers of children with disabilities. Through a series of interviews conducted between April 2012 and February 2013 with immigrant mothers and service providers[1] from organizations such as health, legal, social and developmental services, the study attempted to gain in-depth information on the needs and challenges faced on a day-to-day basis.

The objectives of the Mothers Project were:

1. To understand the perceptions of social support and lived experiences of immigrant mothers of children with disabilities.
2. To understand the perceptions of service providers regarding the needs and challenges immigrant mothers of children with disabilities encounter in accessing services.
3. To inform services and policies to help strengthen the system to cater to the needs of immigrant mothers of children with disabilities.

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[1] Service providers refers to professionals representing social work, health services, lawyers and mediators, schools and other social services agencies who also serve children with disabilities.

Viewed through the lens of lived experience as described by immigrant mothers as well as service providers, this report articulates the challenges and proposes the required steps necessary to strengthen human services. Our findings echo previous research findings and point to a scarcity of information regarding social support for immigrant mothers of children with disabilities. Each immigrant mother of a child with disability has found unique ways of coping in day-to-day life and facing up to the challenges of navigating complex human service systems to find needed help and support. But the physical and mental price of caring is high: tension, fatigue and stress. Many immigrant mothers have minimized their career opportunities in order to maximize the flexibility to provide the best care possible to their children with disabilities. Such decisions increase the risk of poverty and can often take a toll on the health and well-being of the mother. Still, almost all mothers expressed their joy and happiness in taking care of their children with disabilities. The problem, mothers told us, is not a child with a disability; the problem is inadequate structural, instrumental and emotional support systems.

In order to understand and improve the health and wellbeing of all Canadians, including children with disabilities, there is a call for greater policy development on the social determinants of health, as well as more community-based studies that incorporate peoples' lived experiences. This understanding is important because social environments can be modified to improve outcomes for children with disabilities, and the supports required to promote and sustain the health of immigrant mothers.

The report is divided into 6 sections. **Section 1** provides an introduction to rationale and objectives of the study. **Section 2** provides an overview of the key trends, research literature and concepts used to frame the methodology and analysis of the study. **Section 3** describes the research methodology and the ethical considerations. **Section 4** provides the qualitative findings from the study, including quotes from participants. **Section 5** provides policy recommendations based on the study findings. **Section 6** is comprised of study appendices.

2.0   Literature Review – Context and Concepts

2.1   Immigration, Health Status and Health Care

Immigrants make up a significant proportion of the Canadian population. From the total population living in Canada in 2011, about 22% were immigrants, refugees and other non-permanent residents born outside Canada (7,132,150) (Statistics Canada, 2013). Immigration is now the driving force of Canada's demographics, accounting for two-thirds of population growth – compared to one-third for natural increase (Statistics Canada, 2015). Recent estimates suggest that by 2031 immigrants will represent between 25% and 28% of Canada's population (Statistics Canada, 2006). No less significant within this trend is the growing diversity of immigrants in terms of culture, ethno-racial background and religion. The traditional source of immigration, Northern Europe and the US, has

now been superseded by Asia, Middle East, Latin America and Africa. Whereas in 1981 only 4.7% of Canadian residents identified as a 'visible minority', by the turn of the century the number had almost tripled to 13.4 % and has now just over 20% (Samuel & Basavarajappa, 2006; Statistics Canada, 2015). Nowhere is the impact of such ethnic diversity more noticeable than the Greater Toronto Area. In Toronto, 49.1% of Toronto residents now identify as 'visible minority' (City of Toronto, 2013). And indeed, the rates are even higher in other GTA communities: Markham, 73.2%: Brampton, 66.4%; Mississauga, 53.7% (Statistics Canada, 2013). Nor is this process of demographic transformation expected to change with 82.4% of new immigrants of non-European origin compared to about 75% in 2001 (Statistics Canada, 2013; Samuel & Basavarajappa, 2006).

The flow of newcomers is viewed by most to be vital to the country's well-being in the long run – growing the population and bringing new skills and vitality to the social and economic fabric. Among poorer and more isolated immigrant women, access to health-care services continues to be an important issue. In one of our previous studies, immigrant residents from a densely populated neighborhood of downtown Toronto confirmed that despite the presence of health and social services, language barriers and cultural differences often make it difficult for non-French or non-English speaking mothers to obtain the information needed to make important decisions about health, to navigate the health system, and to access appropriate services (Haque, Khanlou, & Montesanti, 2010).

In all, the process of migration and settlement represents a dual threat to the health and well being of immigrants, particularly women. Given that care giving for a child with a disability is identified as factor that can contribute to poor health (Burton, Lethbridge, & Phipps, 2008), the likelihood that the economic and social challenges of immigration and gender will reinforce or amplify the risk of immigrant mothers of children with disabilities is high. Such findings are suggestive that parenting a child with a disability creates another intersection of health risk as institutions, policies and services fail to foster support or adequately adapt to ethno-cultural and linguistic diversity.

2.2 Prevalence of Disability among Immigrant Children

The Global Burden of Disease estimates 95 million (5.1%) children in the world under the age of 15 years have one or more forms of disability, of whom 13 million (0.7%) have "severe disability" (WHO, 2010). In Canada more than 202,000 (3.7%) children under the age of 15 years have one or more disabilities, and approximately 43% of these children have severe or very severe disabilities (Statistics Canada, 2008c). Boys are reported to have higher rates (4.6%) of disabilities compared to girls (2.7%), and among children with a disability, the majority have multiple disabilities (Statistics Canada, 2008c). This has implications for what is still referred to in some of the health care literature as "the burden of care" and consequently the social support needs of mothers. According to the 2001 report of Statistics Canada's survey on Participation and Activity Limitation, only 20%

parents/guardians of children with disabilities reported receiving help with housework, that is, housecleaning and meal preparation, family responsibilities, and time off for personal activities because of their child's condition (Statistics Canada, 2008c).

Reliable prevalence data on child and youth disability among immigrant families is scarce. However, it is widely recognized that children with disabilities are very diverse and are dispersed throughout the urban and rural parts of Canada. These children differ in gender, age, socioeconomic status, ethnicity, and cultural heritage as well as type, severity and number of disabilities. Also, the health conditions associated with disability can be temporary or long term and may be visible or invisible.

As well, 9% of all immigrants admitted to Canada are refugees (Citizenship and Immigration Canada, 2012). The immigration admission criteria for refugees are not the same as those for other categories of immigrant status (e.g., economic immigrants). There is scant information on the health status of children of refugees in the resettlement context. Further research is warranted to understand the extent of the problem and identify the facilitating factors and the barriers in the system for effectively using the services by different groups of immigrant and refugee mothers who have children with disabilities.

2.3 Poverty, Social Capital and Social Exclusion

In Canada, reliable prevalence data for childhood disability in low-income families is currently unavailable; however, an estimated 30% of Canadian children and youth with disabilities live in poverty. In the general population, children in single parent families, children from visible minority families and recent immigrant communities are disproportionately affected by poverty (Petrenchik, 2008). Growing evidence indicates that there are particularly high rates of low income among many racialized groups in Canada with racialized groups making up 20% of the population but 41% of low income households (Galabuzi, 2006). Additionally, low income is more likely to be concentrated among families with children in many of the racialized groups, who make up 29% of all children in Ontario, but account for 51 % of children in low-income families (Ministry of Community & Social Services, 2010).

With the loss of family ties and other forms of social capital due to immigration (Edmondson, 2003), there is a heightened chance of social exclusion and living in a community with low social capital. Three-quarters of immigrants (i.e., landed immigrants and refugees) settle in Toronto and other metropolitan gateways such as Vancouver and Montreal. Too often, such communities possess low levels of social capital (Steptoe & Feldman, 2001) which can buffer the effects of daily life stresses (Belle, 1989) and mediate the detrimental effects of low income (Fone et al., 2007). In combination, low income and insufficient social capital can help forge adverse social and economic conditions with high levels of distress, depression and anxiety (Kazemipur & Halli, 2000).

In the context of poverty, childhood disability means children and families must cope with the added burden of poverty-related health and social inequalities, social disadvantage, stigma and the extra direct costs (time, money, and resources) associated with a child's disability (Petrenchik, 2008). Children with disabilities living in poverty and in new immigrant families are more likely to live in poorer neighborhoods, inadequate housing environments and experience more hardships than other children. They are also more likely to have limited access to necessary health and social services (Bierman et al, 2012). All these disadvantages in turn can contribute to medical complications and secondary disabilities, leading to increased financial burden and family distress (Petrenchik, 2008). The challenges faced by these families are very complex and multi-dimensional, but we currently do not have a sufficient understanding of the specific nature and extent of these families' disability related needs (Rosenbaum, Jaffer, & Russell, 2006). Therefore, in the context of resettlement, a close examination of the intersection of migration with poverty in the families of children with disabilities is needed.

2.4 Conceptualization of Motherhood

Ideas about motherhood and mothering vary in theory and in practice, time and place. Rich (1986) refers to the experience of motherhood as the *potential* relationship of any woman to her children. Further, Rich notes differences between motherhood as a social institution and mothering as an individual practice where women bring distinctive approaches and qualities to their role (Rich, 1986).

The 1980s saw the start of two similar ideas of motherhood, "intensive mothering" (Hays, 1996) and "the new momism" (Douglas & Michaels, 2004). Both require women to be "good mothers" (Thurer, 1994), to devote themselves entirely to their children. Caplan and Hall-McCorquodale (1985) describe the experience of mother-blaming in major clinical journals. Mothers are subjected to an omnipresent "observational gaze", as they are "confined, watched, regulated, adjudicated, and punished" (Wong, 2012, p. 8). The idea of the "observational gaze" is taken from the work of Michel Foucault (Foucault, 1979, 1989) where he describes how observation is used as a means of control so that force is not required. Rather, the subject knows she is being seen and judged, and therefore monitors and modifies her own behaviours to fit social norms. Socio-cultural norms about being good women and good mothers, and as part of the institution of motherhood, determine this gaze. Mothers are judged, not only by professionals and others, including other mothers, but they also judge themselves, as this gaze is internalized as a requisite of good mothering. This gaze intensifies for mothers of children with disabilities. According to Knight's (Knight, 2012, p. 11) review of 40 years of literature on families of children with intellectual disabilities, the accounts of 'good' and 'bad' mothers "continues to form a subtext of this literature".

Much of the care work that women do as mothers is undervalued and invisible (Smith 1986). Even less attention has been paid to the care work of mothers of children with disabilities "despite recognition that it brings heavy, persistent demands, increased costs and disabling barriers" (Home, 2008, p. 147). Home (2008, p. 147) notes that "[a]uthors agree these mothers receive little recognition for their invisible work providing exceptional mothering". Rather than being lauded for their work, for their exceptional mothering, these mothers are blamed for their children's troubles or limitations (Francis, 2010, p. 837). Moreover, children with disabilities are viewed as "social problems" as they may not conform to the expectations of 'normal' childhood and eventual independence, and neither do their parents conform to models of successful parents (Green, 2007).

Mothers of children with disabilities, therefore, find themselves under greater surveillance, including from professionals (Ryan & Runswick-Cole, 2008). Because mothers of children with disabilities "regularly alternate between the roles of mother, nurse, therapist, and doctor", they are in more frequent contact with physicians and educators, and "may find themselves embroiled in prolonged disputes with medical, educational, and bureaucratic professionals" (Francis, 2010, p. 837).

In addition to disability as a marker of difference, social status as immigrants or refugees puts these mothers under yet more social surveillance. Canadian immigration policy between 2008 and 2012 underwent unprecedented and significant changes to policies and programs that impact immigration, temporary residency, and citizenship (Alboim & Cohl, 2012), and therefore families. Given a "less welcoming environment for immigrants and refugees" (Alboim & Cohl, 2012), newcomers to Canada are faced with increased scrutiny, requirements and restrictions, affecting their quality of life. One significant policy change in 2011, is that in the family class of immigrants, a moratorium has been imposed "on the sponsorship of parents and grandparents and created a super visa for them to enter Canada as visitors" (Alboim & Cohl, 2012). This imposes additional challenges for immigrant mothers who would benefit from the support of their own parents in that grandmothers of children with disabilities can play a critical role as a source of support for their families (Gallagher, Kresak, & Rhodes, 2010; Neely-Barnes & Dia, 2008).

2.5 Conceptualization of Child Development – The Human Ecological Model

Child development refers to growth of a child in all aspects of human functioning such as social, emotional, cognitive, communication and movement. The current conceptualization of child development emphasizes the importance of both genetic predisposition and the external environment and involves an interaction between the two. This conceptualization, which incorporates both genetic predisposition and external environment, parallels the bio-psychosocial model of health (Engel, 1977) and builds on Bronfenbrenner's ecological model (Bronfenbrenner &

Ceci, 1994). The model helps us to understand how human development takes place through progressively more complex interactions between an individual and the persons, objects, and systems in their immediate and distal environments – the micro, meso and macro. Figure 1 (below) illustrates a practical schema for this theory.

- **Micro Environment:** The inner circle represents the most proximal environment of the child, family and caregivers. The arrows between the members signify the relationship and interaction between the members. The intersecting arrows indicate how relationships between one pair shape and influence others in the system.
- **Meso Environment:** The second circle includes the larger community, and various services and physical environments that the child interacts with on a day-to-day basis. These factors directly influence the development of the child, through the living and working conditions of the parents/caregivers, the school system and the availability and quality of the health and social support services (Ertem, 2012) available to the child and the family.
- **Macro Environment:** The outer circle represents policies, legislation and fiscal factors which indirectly affect the child's development by shaping and influencing the meso environment and, ultimately, the micro environment.

Figure 1 Conceptualization of child development **(**adapted from WHO, 2012[2]**)**

Figure 1. Conceptual Model: Socio-ecological model (adapted from WHO, 2012)

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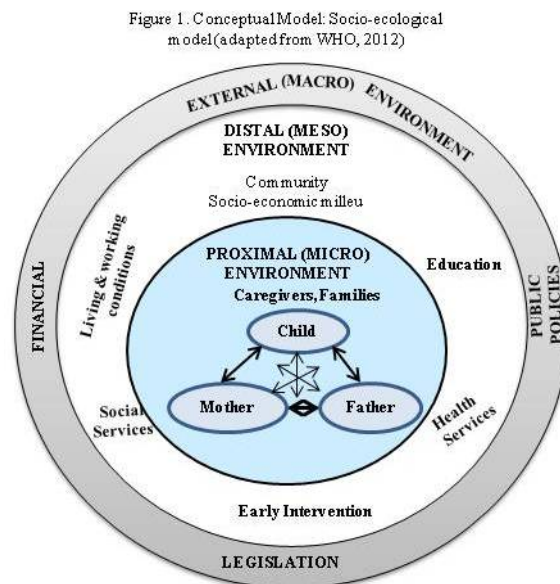
[2] Adapted from Review Report by World Health Organization (2012, p. 8). *Developmental Difficulties in Early Childhood. Prevention, early identification, assessment and intervention in low-and middle-income countries* .

As the ecological model suggests, social support is not simply what is available within the family and their immediate neighbourhood and social network. Children's development is not only dependent on what happens within the family, and the immediate environments in which children spend their time but is also influenced by their parents 'world of work' and their social networks (Bronfenbrenner, 1986). Equally important, support from the macro level can include formal factors such as national and provincial policies that establish (or hinder) systematic access to services and supports as public policy influences what services are funded as well as how services are delivered (Neufeld et al., 2002). For example, child development is dependent on the linkages between the family and other major settings, such as hospitals, daycare, peer groups, schools, social networks, employment (both for parents and children), neighborhoods. Ultimately, the macro system level helps to shape the availability, accessibility and flexibility at the meso and mico levels through legislation, regulation and rules, as well as an impact on political discourse and social attitudes (Petrenchik, 2008). Critical to understanding the ecological model is recognizing the influence and interaction within and between the macro, meso and micro environments. No single level can be fully understood in isolation with conditions and factors at one level having an impact, however indirect, at other levels.

2.6 Conceptualization of Social Support – Structural, Instrumental, Emotional and Perceptive

Formal and informal social resources have been shown to shape health and wellbeing. Social support is a major adaptive resource for mothers of children with disabilities. It acts as a protective factor and helps mothers to ease their stress and adjust to life with their child (Hendricks, de Moor, Oud, & Franken, 2000; Pelchat, 2007) and acts as a source of health (Edmondson, 2003). Understanding social support necessitates a framework distinguishing between the various types of formal and informal support at the macro, meso and micro levels.

House (1981) suggests that social support is comprised of four distinct types of support: structural, instrumental, emotional and perceptive. Our framework further connects the four types of social support with the macro, meso and micro levels of the child development environment:

Structural Support (Macro): Refers to the public policies and practices of social systems and institutions that help establish an overall supportive living environment.

Instrumental Support (Meso): Instrumental support is tangible support such as provision of financial assistance, material goods, or services (House, 1981). This form of social support encompasses the concrete, direct ways people assist others (Langford, Bowsher, Maloney, & Lillis, 1997). Such support and aid can come from formal service institutions as part of the social safety net, or through networks of family and friends (often concurrent with emotional support as the sharing of experiences, sorrows and joys).

Emotional Support (Micro): Emotional support is the warmth and attention provided by sources of social support. It involves the offering of empathy, concern, affection, trust, acceptance, encouragement, or caring when needed (Burton, Lethbridge, & Phipps, 2006). Providing emotional support can let the individual know that he or she is valued. In the literature, emotional support is defined as support that gives the individual a feeling that they are cared for, or the provision of "empathy, caring, love, and trust" (Ling, 2000). Emotional support strengthens the individual's feelings of self-worth and belonging, affirming their coping efforts (Kierans et al., 2008).

Perceptive Support (Micro): Perceptive support relates to individuals' judgments and impressions regarding the social support system available to them, and how individuals form impressions about how others affect their personal lives. Individuals who have positive perceptions and believe that emotional or tangible support is available to them if needed may help them to spend less time worrying about their daily life problems and hassles (Peirce, Frone, Russell, Cooper, & Mudar, 2000).

3.0   Research Methodology – A Brief Overview

The study design was based on the application of a descriptive qualitative approach (Sandelowski, 2000). In-depth telephone interviews were conducted with immigrant mothers who had children with disabilities to explore their experiences in relation to structural, instrumental, emotional and perceptual support. In-depth interviews were also conducted with service providers, to understand their perspectives of the challenges faced by mothers. Data was collected between April 2012 and February, 2013. All interviews, except one with a service provider, were conducted over the telephone at a mutually agreed time. Each interview lasted from 1.0 to 1.5 hours. Following verbal consent from participants, detailed notes were taken by the interviewer.

Two groups of participants were recruited: (1) immigrant mothers of children with disabilities, and (2) service providers. The criteria for including mothers in the study were: (i) immigrant mothers, (ii) have one or more children with a disability or disabilities, (iii) feel comfortable speaking in English. Service provider participants were recruited from organizations representing social work, health services, law and other relevant service providers who provided services to children with disabilities and/or to their families.

Interview guides for mothers and service providers were developed by the principal investigator and research coordinator. The mother's guide was informed by existing literature (Harknett & Knabb, 2007; Miller, Gordon, & Diller, 1992; Skrinda, 2008). Following each interview, the research coordinator recorded notes of observations and insights in a field log. For a select number of interviews, the interviewer and principal investigator discussed the interviews/insights immediately after the phone interview. In all cases, extensive field notes were attached to each transcript, as well as inclusions from discussions of findings during research team meetings. The purpose of the filed notes was to help contextualize the findings and assist with analysis.

A variety of steps and methods were used to ensure the rigor of the data for analysis. Sources of data for analysis included transcription notes from the interviews and the field log. The transcription notes were entered in Dragon software and field log notes were used as a reference to contextualize the findings. Data triangulation was done by collecting data from mothers and service providers and investigator triangulation was achieved by using multiple coders (Bennett, Deborah, & Allen, 1996; Stainback & Stainback, 1988).

4.0 Hearing the Voices of Immigrant Mothers of Children with Disabilities- Study Findings

4.1 Demographic Characteristics of Participants

A total of 57 participants were interviewed in this qualitative study. Of these, 30 participants were immigrant mothers of children with any form of disabilities and 27 participants were service providers. Tables 1 and 2 describe the characteristics of the study participants.

Mothers: The mothers in this study immigrated to Canada from various countries as illustrated in Figure 2. The age of mothers (mean) was 42 years[3]. The mean length of stay in Canada was 10 years. Twenty-five mothers reported being currently married and five mothers reported being single. For each mother, the number of children they had ranged from 1 - 5. Mothers had a total of sixty-seven children. Of these, thirty six children experienced one or more disabilities. The ages of children ranged from 0.66 – 42 years and the mean age reported for diagnosis of their children's disability was about 30 months. Most mothers reported having one child with disability; however, six participants in the study reported having two or more children with disabilities. A range of disabilities were reported by mothers: autism, hearing impairment, learning disability, language disability, cognitive impairment/seizures, attention deficit hyperactivity disorder, Asperger's syndrome, pervasive developmental disorder, and brain injury.

Fig. 2 Mothers Origin
N=30

3% 7%   7%
40%   20%
23%

- Africa
- Carribean
- East Asia
- Europe
- South Asia
- Middle East

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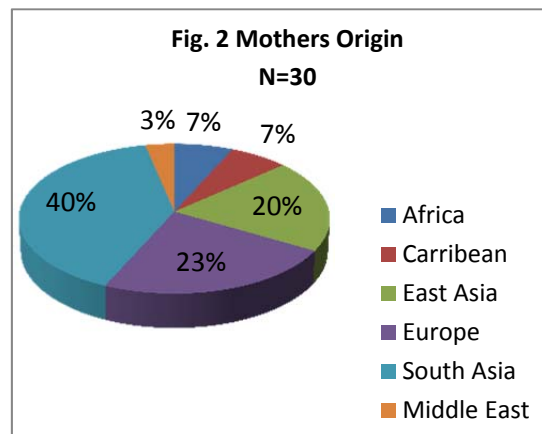
[3] Numbers are rounded either up or down to the nearest integer.

Table 1 Characteristics of Participants: Immigrant Mothers of Children with Disabilities

Demographics of Mothers	Mothers N=30
Age in Years	
Mean	41.6 years
Range	31 – 66 years
Marital Status	
Currently married	25 (83.3%)
Single (separated/widowed/divorced)	5 (16.7%)
Number of Children per woman	
Mean	2.2
Range	1 - 5
Gender of Children (n=67)	
Male	45 (67.2%)
Female	20 (29.9%)
Missing	2 (3%)
Age disability diagnosed	
Mean	30 months
Range (months)	0 – 84 months
Years lived in Canada	
Mean	10.4 years
Range (years)	0.33 – 42 years
Region of origin	
South Asia	12 (40%)
East Asia (Japan/ Philippines/China/Taiwan)	6 (20.0%)
Middle East (Palestine)	1 (3.3%)
Europe (East & West)	7 (23.3%)
Caribbean	2 (6.7%)
Africa	2 (6.7%)

Service providers: The social service needs of children with disabilities and their families are complex and involve providers ranging from diverse disciplines and in different settings. Figure 3 illustrates the types of professionals who participated in this study. The mean number of years of experience of participants in their respective professions was 13.7 years. The providers reported working in various organizations such as schools and school board, CHCs, ombudsman's office, and children's treatment centers (Table 2).

Fig. 3 Types of Service Providers N=57

- Manager — 22%
- Social Work/ Mediator/Counselor — 41%
- Law / Advocacy/Politician — 26%
- School trustee — 4%
- F.Physician/Pediatrician — 7%
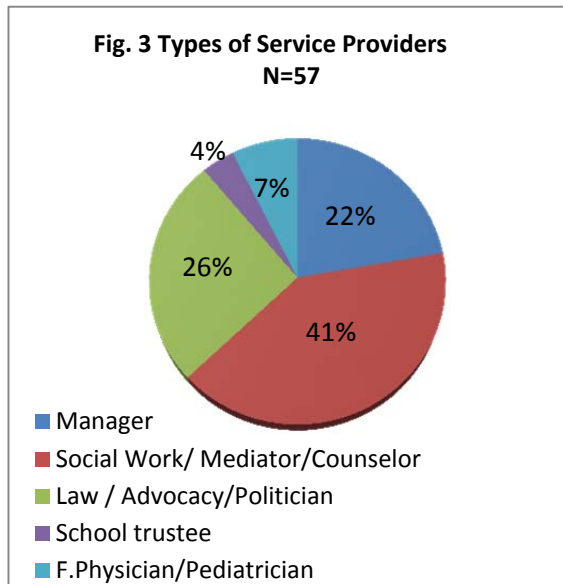
Table 2 Characteristics of Service Providers

Description	N= 27
Occupation	
Social worker/Family mediator/Counselor	11 (41%)
Manager	6 (22%)
School trustee	1 (4%)
Law/Advocacy	7 (26%)
Family Physician/Pediatrician	2 (7%)
Gender	
Male	5 (19%)
Female	22 (81%)
Types of organization	
Child treatment/Autism/ Epilepsy centre/ Hospital	9 (33%)
Law/Ombudsman office/Advocacy	7 (26%)
Community/Neighborhood centre	5 (19%)
Academic	3 (11%)
Self employed/Support group	3 (11%)
Years involved in work	
Mean	13.7 years
Range	2 - 35 years

4.2 What Mothers Told Us About Structural Support

Structural support refers to the public policies and practices of social systems and institutions that help establish an overall supportive living environment. An effective client centered health and social services system should consider the needs of both the parents and their children, and the programs should be centred on families. Other studies have found that for all new immigrant families, the process of immigration is stressful as they try to learn the rules, health and schooling systems, and social engagement rules of the host country (Falicov, 2003). Compounding these challenges is the need to foster a new network of social support (Suárez-Orozco, Suárez-Orozco, & Baolin Qin-Hillard, 2005; Suárez-Orozco, Suárez-Orozco, & Baolin Qin-Hillard, 2001). Adjustment to a new environment is even more difficult when one or more of the children have disabilities and require extra care. Amplifying what is already a challenge for most families of a child with disabilities, immigrant mothers face further barriers and complexities such as English as a second language and cultural differences, such as how they define the nature and cause of their children's disabilities and how they follow up with treatment and professional support (Kummerer, Lopez-Reyna, & Hughes, 2007). Some believe that if they ask for help, they will lose their migration status. Others are hesitant to admit their children's disability to relatives, neighbours and friends believing that the disability of their children is a result their past sins. In essence, cultural beliefs and stigma can serve to increase the risk of social isolation.

Participants expressed multiple challenges and barriers in accessing social services for children with disabilities, especially services that met their needs. Both mothers and service providers spoke of issues such as bureaucracy, language barriers, lack of knowledge and availability, limited information, dispersed and disjoint services, lack of documents and evidence, discrimination and financial limitations, as some of the barriers faced by immigrant mothers of children with disabilities.

Our study found that these hardships were even further multiplied for those with lower income, education and/or language skills. Consistent with findings from other research, mothers with higher education and affluence were more confident asking for help, seeking out social services, and using private facilities, all of which resulted in the provision of care for their children with minimal or no delay (Leong & Lau, 2001). On the other hand, mothers with language barriers or financial limitations were hesitant to express their children's needs. As well, many mothers reported trying to solve issues themselves. Under structural support we explore the following: complicated system, excessive paper work, dispersed services, linguistic barriers, long wait ties, cost of services, lack of awareness of client needs by service providers, racism and discrimination, cultural acceptability of social services, family and school services, and youth transition.

The first time of the diagnosis of a child with a disability or disabilities can be particularly very stressful for immigrant mothers and their families. Sloper (1998) described it as an event which is traumatic for parents. The diagnostic news may make mothers go through stages of shock, denial, anger, shame, and depression (Sloper, 1998). Mothers who have difficulty in overcoming this distress in the initial phase may later encounter difficulty in taking proper care of their children; thereby, having a significant impact on proper growth and development of their children (Sloper, 1998).

Some respondents did report high levels of distress and difficulties in accepting and adjusting to the knowledge that their child had a disability.

Our study findings corroborate with previous findings, hardships are more severe in those with poorer language skills, lower socioeconomic status, and lower education levels. Mothers with language barriers or financial limitations were hesitant to express their children's needs. This could be due to a fear of being considered demanding, and could lead to these mothers becoming more marginalized and invisible.

> *When he was first diagnosed, I had very strong denial…. It was really, really hard for us – emotionally tough (M 5).*[4]

Complicated System

The systems of services were recognized by mothers and service providers to be complicated. Services providers described the difficulties mothers were encountering in accessing services. A service provider described the main barrier for immigrant mothers in accessing services and supports for their children with disabilities in these words:

> *Many of my clients do not have a caseworker or social worker to work with. What is needed is a central person to whom immigrant families can go to ask what is available* (SP3).

> *There is a general lack of understanding of our system. Families were unsure where they can go to access resources and to investigate services. It is very difficult for them to get such information (SP 3).*

> *The system is really complicated. Even for me it is really complicated as a professional.... It is not the language barrier issue, the issue is what services are available…. The name of service providers is very confusing. There are many different agencies. There is an overlap and there are gaps in service provision…. It is an issue of not knowing where to go. We need one central place of access. It is easier for immigrant mothers to access services for children up to the age of 12. After the age of 12 they don't know where to go. And once children with*

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[4] A number of direct quotes in this report have been slightly edited for grammar for readability purposes.

disabilities turn 18 it is very problematic, they are on their own.... The main difficulty is that forms are very long and complicated.... It is discouraging. It is like a full time job there is so much work to coordinate. Another problem is when they go through one service provider they are shifted to people elsewhere. What the mothers need is someone who will sit down with them and fill out the forms for them and provide them with advice (SP 7).

Mother participants expressed similar concerns and the many challenges they face in their day-to-day life.

What would be helpful would be having a one-on-one person to give you a specific name; and you can pester them. There is unfortunately no other way to get a response. My advice is always get the name of the person who's responsible. If they say it's not my department, ask them whose is it? And follow up with them. I'll call back every three days.... They will know me by my voice (M 13).

Excessive Paper Work

Both mothers and service providers stated excessive paper work, due to long and complicated forms, as a major barrier in accessing services. Such paperwork can discourage and generate additional stress.

Even for us (service provider) the forms are complicated (SP 7).

For 200 bucks, 20 forms, witnesses, signatures – I'm just struggling to survive! … It's really amazing that the parent can't be the caregiver [referring to respite workers funded by government] (M 3).

Dispersed Services

Immigrant mothers are spread across the Greater Toronto Area (GTA) as are the location of agencies that provide services for children with disabilities. Transportation for mothers and their children for access to and use of these services were among the primary concerns of mothers in this study.

One school had an autism unit! It was 45 minutes away. We went at 6:55 am. A driver comes to get my daughter. They had to drive for 50 minutes and get home before 2:30 pm, so I cannot do any work (M 9).

For me language was not a barrier. But there are a multitude of agencies, with services scattered all over the place. There are so many. It took so much time, so much energy, so many services, faxes of diagnoses all over the place. So much…. [We need] just one agency to provide proper support to us. Every one gives you a support booklet and you start digging when you should be taking care of the child (M 25).

Linguistic Barriers

Many participants highlighted language as a major barrier in accessing services. Service providers explained the difficulties immigrant mothers' face in understanding the language of legal matters:

> There is a general lack of knowledge and the language is an issue even with regards to the documents that are being filed with the court or used in the process they are involved in. It's a maze. It's very challenging for immigrant women unless they have a lawyer or a community advocate to help them along the path *(SP 12)*.

> The language issue is huge if the person is not comfortable with English. It's very significant if the person is not comfortable English. But if English is not the issue then it [the barrier] could be the new immigrant's understanding of the system *(SP 13)*.

> Families have difficulty with terminology. What is respite for example? Maybe they need respite, maybe they don't need it…. They may need help to maneuver through the service delivery system *(SP 20)*.

Long Wait Times

Service providers and mothers expressed their concerns and frustration regarding long waiting time and mothers not knowing when their time will come:

> I don't know if anyone has mentioned about special services at home (SSAH) to you [interviewer]. There are families that have it and there are families that don't. It's longer than three years to restructure *(SP 13)*.

> The wait list in the north of Toronto is 4 years. I got on in one year and three months in my area. Who organizes the waitlist and how? Everything is hidden. There is no visibility *(M 26)*.

Cost of Services Including Transportation

Mothers underlined their inability to bear the financial costs of many of the tests and services that are not covered by government but are required for proper diagnosis and/or development of their children.

> We were eight months on a wait list, so we went with private [speech] therapy, which was out of pocket in the beginning – $125 per session. My husband is not making that much money *(M 19)*.

> I have four kids…. This [day care] is one of our problems. We could not find anyone. We could not afford it. For who is willing to babysit?... Others are qualified but are resistant because of the communicative issues. With two or three kids we couldn't afford $20 per hour for me to go to work for $12 per hour *(M 13)*.

There were sensory tests and other tests recommended by ... that I cannot afford. Four weekends cost $50 a week to put the child with a babysitter (M 3).

I have to work to support the needs of my family. If I do not work I lose the speech therapy through work benefits. I need this. I needed this when he was three and got his diagnosis. They told me to put him in daycare for exposure with typical kids. We have to pay out of pocket.... I need to work for benefits (M 11).

Lack of Awareness of Client Needs by Service Providers

Participants in the study expressed their concerns about inadequate awareness regarding the needs of children with disabilities even among professionals. They also pointed to the gaps in the existing programs. In general mothers were satisfied with the services of the family doctor. However, some mothers expected their family doctor's office to be more sympathetic to their situation and provide emotional support to help them cope. They also expected their family doctors to provide more information on service availability for their children.

Families [who] come here [neighbourhood center] are not fluent. The first person they will try to find is their language specific doctor. The doctor will deliberately under-report the severity of the disability.... One of my clients ... has a daughter with severe disabilities who was denied assistance for children with severe disabilities (ACSD). Her doctor did not report the extent of needs ... [doctor] would not fill out the ACSD forms properly.... [Doctor] didn't say the child might need a bliss board and a specialist in Toronto. The doctor did not project enough. The worker did not project enough.... They will deny the client the necessary coverage (SP 21).

One Dr. was useless. More education amongst service professionals is needed. I got help from others, not professionals. Then you go to professional to tell them what it is I need. It's the wrong way around; maybe this is a systemic problem (M 8).

Administrators have no understanding of how disability works (SP 8).

I have to say some pediatricians are not supportive. They have been practicing a long time – they need to be updated. They are not a good resource. She asks questions, checks the height. We need someone who's helpful and gives information (M 10).

Disability awareness as a whole is a problem. Yes, there is a special needs' unit. Some children aid society workers don't know what assistance is available for children with severe disabilities! They need to know more about that whole world (SP 18).

There is no outreach for newcomer moms. We have to better understand how different cultures frame disability, and settlement services are key places of safety to do this (SP 19).

> *I would have appreciated more information on what was available from the family doctor. The doctor is your first line. There's the diagnosis. They could have all the information about other supports and services to give out. I was very disillusioned with the doctor. When they give the diagnosis – that could be therapeutic, emotional support that could help (M 6).*

> *Most important is that the health care provider would be the main key person with concerns with the child, who could help and assist with the services available and connect us with an agency that would give us more information (M 11).*

Racism and Discrimination

Racism and racial discrimination are often used to describe discrimination on an ethnic, cultural or racialized status basis. The term "race" also implies stereotyping, exclusion and other forms of social injustices (Harris et al., 2006). According to United Nations Convention, there is no distinction between racial discrimination and ethnic discrimination (Jessri, Farmer, & Olson, 2013). Racial discrimination can occur at either the interpersonal level or institutional level. Institutional discrimination refers to discriminatory policies and practices that are entrenched in the structures of organisations and, therefore, becomes invisible and difficult to detect (Harris et al., 2006). Such discrimination can create barriers for immigrants in accessing the health and social care systems and appropriate services (Newbold, 2005).

Some participants were concerned by the negative attitude and discriminatory remarks made by some of the service providers in the education sector.

> *There are cultural issues. People must be aggressive and assert themselves. Many feel uncomfortable. Things can get way out of hand and then they need support. Immigrant parents are not sure what their rights are and so it's easier to push them aside (SP 26).*

> *The schools are reluctant to give kids support. A lot of kids have problems and are put into the lowest class with a developmentally delayed program … it is like daycare…. Here if you are immigrant and black it is hard to get things done. There are racial inequalities; it is harder for black, Indian, Chinese…. Kids with autism like to touch things and the school put in his IEP "inappropriate touching". This was offensive (M 2).*

Cultural Acceptability of Social Services

Immigrants are a diverse population and so are their cultures and belief systems. Mothers' cultural beliefs and values influence how they define the nature and cause of disability, and how they follow up with treatment and professional supports. Acceptability here means cultural acceptability or cultural appropriateness of services for immigrant populations. Services must be linguistically and culturally appropriate to be considered truly accessible. Immigrant mothers may face language barriers and a lack of familiarity with the system (Steele et al., 2002). Mederios (1991) found four

systemic barriers to access to acceptable family services for ethno-cultural and racial communities in Toronto: (1) lack of recognition of ethnicity and racial factors; (2) lack of capacity to address language needs; (3) inappropriateness of methods of service delivery; and (4) location. In our study, most mothers stressed the issues of service accessibility, whereas many service provider participants raised issues related to culture and language as important barriers in accessing appropriate services.

> The stigma born by a child with disabilities in other cultures and in the dominant culture is a barrier…. For example for South Asian cultures there is more stigma associated with having a child with disability **(SP 2)**.

> Disability is a social taboo in some of cultures…. Some individuals will blame the child for being disabled. Some communities blame the women for having had a disabled child **(SP 11)**.

> Culturally, some mothers become isolated because they don't want to be a burden to others, like Japanese mothers, versus Latin culture. They are more collective and more expressive **(SP 7)**.

> In South Asian culture, the father has special place. Mother is a 24/7 caregiver, but the father is making decisions. This style is challenging sometimes because the father may not be realistic in his expectations for the child's behavior, and challenge for the child remains unseen **(SP 2)**.

The Family and School Services

It is well established in the literature that the relationship between mothers/families and school has a powerful effect on the capacity of a child to learn in the classroom. Most mothers spoke about the negative experiences they had with the school system. They had difficulty in navigating the education system and faced challenges in accessing the dispersed services. Mothers described their experiences of school in these words:

> At first the school was difficult. We didn't know anything…. We were not familiar with the way things are in the education system here **(M 23)**.

> You need good cooperation between home and school. It's very important right now … communication is his one big disadvantage…. I haven't worked with the teacher to work out the system … for his communication **(M 28)**.

Youth in Transition

Youth in transition is the phase referring to individuals between the ages of 16 and 25 years. Youth with disabilities are likely to need continuing support for daily activities into adulthood. Yet, youth in this transition phase are not eligible to access child-serving services and are not ready to access young adult services even when they need them. The lack of transition services availability may contribute to poor outcomes (O'Mahony, et al., 2012; Ray, Henry, & Urquia, 2012). Participants expressed their concerns and frustration for not being able to access services for their adolescent children with disabilities.[5]

> *The biggest issue now is kids over 18…. There is a 20 year wait list in group homes in Ontario* ***(SP 8)***.

> *It is easier for immigrant mothers to access services for children up to the age of 12. After the age of 12 they don't know where to go. And once children with disabilities turn 18 it is very problematic, they are on their own* ***(SP 7)***.

4.3 What Mothers Told Us About Instrumental Support

Instrumental support is tangible support such as provision of financial assistance, material goods, or services (House, 1981). This form of social support encompasses the concrete, direct ways people assist others (Langford et al., 1997). Under 'instrumental support', we explore the following: (i) Support from family and friends; (ii) Support from extended family; (iii) Support from informal networks; and, (iv) Support from service providers.

 Support from family and friends

Research suggests that husbands are the main source of support to the mother. Other studies have shown that extended family members and friends also play an important role in providing advice and information to mothers. However, family members are described as more important sources of material and physical support, including respite care (Bennett et al., 1996). Paradoxically, family members could also be a source of stress for mothers if they were perceived by mothers to be judgmental and critical of their caretaking skills. For example, having a husband is also a significant

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[5] Our Office is conducting a community-based study on young adults with developmental disabilities (YADD study) which aims at addressing some of these financial and social equity issues faced by youth and their families. We are conducting interviews with young adults (ages 19-29), with their family caregivers and with service providers who serve this population.

predictor of stress and adjustment in mothers (Bennett et al., 1996; Bristol, Gallagher, & Schopler, 1988).

> *My husband was not spending time with our son. He had two jobs to support the child. He was in denial. As a mother and as a teacher I could see it [child's needs]. I took him [son]… in my two hours time off at work for speech therapy. It was emotionally a very rough time.... He [husband] works twelve hours 5:30 – and is home at 7:00…. He [husband] came to some therapies* **(M 12)**.

> *It is devastatingly difficult to care for these children. Immigrant mothers are less likely to carpool, less likely to have friends who could pick up groceries for them [and over time because of intense demands] friends fade away* **(SP 20)**.

> *My neighbours don't understand [her child]. I wouldn't trust that. I have never left her with anybody actually, except her father* **(M 20)**.

Support from extended family:

The loss of social networks and social support from extended family and friends following immigration to Canada was an important concern expressed by mothers.

> *Yes, as an immigrant you don't have close friends from childhood, or the community. You feel isolated. You exaggerate the negative side and not the positive. With help of family members it gives you a different perspective and it pulls you out* **(M 29)**.

> *They feel comfort speaking to someone who has been through it and who has walked that path. They prefer that to someone who's gone to school for it* **(SP 22)**.

Support from informal networks:

Support group members provide each other with various types of help. They may take the form of providing relevant information, relating personal experiences, listening to and accepting others' experiences, and providing sympathetic understanding and support. A support group may also engage in advocacy and support social change. Mothers who belonged to a religious group were happy with the support they received from their support group.

> *They [church group] are a big strength to me. They are socially supportive. It is a closely-knit church and more like family to me. They are there to support me from every side* **(M 27)**.

> *I attended a … [session at service organization]. I have texted and Facebooked friends there – moms and sometimes we meet with our kids…. I think iPhones and cell phones are the best invention for depressed moms with high needs kids…. We can give support even through a message* **(M 28)**.

Support from service providers:

Mothers of children with disabilities are in constant contact with one or more service providers. Service providers are increasingly being considered as a "partner" and an important source for providing formal and informal support to mothers to cope with their stress (Bennett et al., 1996; McCallion & Toseland, 1993).

> *Psychologists were supportive and talked about issues around child wellbeing. They helped [her] on the issue of diet for [her] child with autism and suggested alternative therapies **(M5)**.*

> *They [service providers] tell me to go online. Life is not easy – it's a wild goose chase. I have four graduate degrees; I get lost on the website **(M3)**.*

4.4 What Mothers Told Us About Emotional support

Emotional support is the warmth and attention provided by sources of social support. It involves the offering of empathy, concern, affection, trust, acceptance, encouragement, or caring when needed (Burton, Lethbridge, & Phipps, 2006). Providing emotional support can let the individual know that he or she is valued. In the literature, emotional support is defined as support that gives the individual a feeling that they are cared for, or the provision of "empathy, caring, love, and trust" (Ling, 2000). Emotional support strengthens the focal individual's feelings of self-worth and belonging, affirming their coping efforts (Kierans et al., 2008).

Mothers perceive the emotional support that they receive from their husbands as more important than their help in caring for the child (Bennett et al., 1996; Kazak & Marvin, 1984). Many of the mothers who participated in our study reported being satisfied with their spouse's involvement with the child. However, in practical terms these mothers assumed most of the care of the child and felt more responsible for the care and upbringing of the child with a disability. The father's main role was that of a provider. The distribution of parental responsibilities may be assessed by the following observations:

> *He [husband] supports me in my decisions and how we raise them **(M 3)**.*

> *My husband is supportive to me, but he doesn't interact with the children as much as I want him to. When he comes home he just wants to relax. Not like me…. He's not bearing the same amount of work that I do with the kids **(M 23)**.*

4.5 What Mothers Told Us About Perceptive Support

The relationship between social support and health is well established (Adler & Matthews, 1994; Cohen, 2004; House, Landis, & Umberson, 1988). Perceptive support relates to individuals' judgments and impressions regarding the social support system available to them. It also helps mothers to form impressions about how others affect their personal lives. These impressions are usually based on observations; however, their decisions for utilizing available support and services are strongly influenced by their perceived support. Individuals who have positive perceptions and believe that emotional or tangible support is available to them if needed may help them to spend less time worrying about their daily life problems and hassles (Peirce, Frone, Russell, Cooper, & Mudar, 2000). The following comments illustrate mothers' feelings based on their positive/negative assumption of perceived social support.

> I have friends who are mothers without disabled children…. I cannot rely on them … I feel isolated **(M 1)**.

> As an immigrant I had no family, I had a few friends but we moved a lot. However, I made a couple of friends in a parent group and I am still friends with them…. One of the most important things is to speak to others in the same situation **(M 6)**.

4.6 Mothers' Resiliency and Advocacy

Immigrant mothers in this study reflected on their ability to cope with stress and demonstrated their individual attributes of perseverance, hard work, determination, and strength. Resiliency provided mothers the energy required to move on and fight for their child's rights. Service providers interviewed also attested to the unmet needs of mothers as well as their problem solving and advocacy skills, and their strength and resilience.

> The mothers don't give up. They are persistent on the issue of advocacy for their children. They go after resources, they follow–up on the smallest leads, they follow through where resources are. More resources and supports are needed. Their tenacity comes from their desperation for resources and supports **(SP 11)**.

> They find ways to survive… The bamboo is resilient, it won't bend … it is hard to break…. Some women are persistent but some will hold back and they will do that to save face **(SP 8)**.

> Immigrant mothers are very good researchers…. They are not hesitant to contact professionals. They make use of personal networks effectively to get information. They get some information from the Internet. They support each other around their children's educational issues **(SP 5)**.

Mothers, through their journey of parenting a child with disability, became strong advocates for their children as evidenced by the narratives of some of the participants.

> *Mothers are advocates for their kids... they rise over their own issues* **(SP 7)**.

> *Even if you don't have the money you know you have to make it right…. You can always do something to get money. As a parent you don't have a choice* **(M 4)**.

> *They are amazingly strong and master what it takes to take care of these children…. Parents of children with complex care needs are heroic whether they are immigrants or not* **(SP 20)**.

> *Families are persistent; they know what they want and they make demands* **(SP 9)**.

> *They become advocates battling government…. First, communication is an issue…. And second is navigating the system and not knowing how to navigate the system* **(SP 8)**.

4.7 Summary: Persistent Challenges, Advocacy, Pride

The findings of this study on immigrant mothers of children with disabilities corroborate with previous research findings on non-immigrant mothers of children with disabilities. Each immigrant mother of a child with disability generally found their own unique ways of coping with their situation and navigating the complex system to find the services needed for themselves and their children. Most mothers in the study acknowledged that taking care of a child with disabilities is a long-term commitment and it causes mothers to live their lives under constant tension, ongoing fatigue, and emotional stress due to concerns about their children's education, health and wellbeing[6]. Many mothers affirmed that they were overwhelmed with work, complexity of navigating the system and care giving and parenting responsibilities with very few resources at hand. Some mothers stated that in order to cope with work, they either gave up their jobs all together or joined precarious jobs to have the flexibility to cater to the needs of their children with disabilities - risking the possibility of the family moving into poverty. These findings are similar to WHO's research findings from select European countries (WHO, 2010). In our study almost all mothers referred to long waiting times, dispersed services and financial issues as major challenges in accessing services.

In general, mothers appreciated the advice and help they received from most service providers, although some mothers said they would have appreciated if their family doctors had provided them

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[6] Our Office conducted the community-based study "Health Promotion of Immigrant Mothers of Children with Developmental Disabilities: What is Relevant?" which examined the mental health needs and health promotion strategies immigrant mothers suggested n interviews. For more information please check the project Information Sheet at http://nkhanlou.info.yorku.ca/files/2014/12/Info-Sheet-7-Health-Promotion.pdf

with information for other services. Many mothers voiced their challenges with the school system and expressed their dissatisfaction with the school system's accommodation of children with diverse disabilities. Some mothers expressed their concern about educators' negative attitudes towards them. Participants talked about the lack of some providers' awareness of the needs of children, providers' discriminatory attitudes towards them, inflexible administrative procedures, and lack of coordination between the service providers. The service related issues voiced by mothers were echoed by the service providers as well. These study findings reverberate with WHO Regional Office for Europe (2010) research findings from select countries in the European region.

While mothers of children with disabilities spoke about the many challenges and difficulties they faced in their daily life, almost all mothers expressed their joy and happiness in taking care of their children with disabilities and were willing to do whatever needed to ensure their children's optimal growth and development. They emphasized how important it was for them to make sense of their children's disability, their happiness in advocating for their children, and helping other mothers by sharing their own stories with them. Mothers voiced that one solution to every problem does not work and service providers should have a better understanding of each mother's life and family context to be able to tailor the services to their particular needs.

5.0   Recommendations and Policy Implications

The Convention on the Rights of Persons with Disabilities (CRPD) recommends that national health policies address health inequalities to remove health disparities among people with disabilities (WHO, 2011). It specifically states that discrimination against people with disabilities when accessing health or health related care should be eliminated. It further states that policies should ensure that people with disabilities receive the same quality of services as other people and early intervention and treatment services to be as close possible in their communities (WHO, 2011).The social support services for families of children with disabilities must be comprehensive, intersectoral across systems, such as health, education, welfare and social services. However, one size will not fit all and flexibilities within programs are needed.

The UNICEF (2013) report makes a powerful statement that "inclusion goes beyond integration. It is not enough merely to grant children with disabilities access to classrooms, facilities, resources, and roles from which they may have previously been excluded. Access alone is not enough to bring about the changes needed. It is the fundamental rethinking of what these children have to offer that has to change" (The Lancet, 2013).

Tier 1: Structural or macro-level support

Everyone should have equal opportunity to reach their full potential for health and become productive and valuable members of society. Yet, many disadvantaged populations including children with disabilities among immigrant families, often experience reduced access to social support and health services as compared to their non-immigrant and higher-income counterparts. For services to be effective, increased awareness, availability, accessibility and affordability of the services need to be ensured for all children and families of children with disabilities. In the case of immigrant families, the added intersection of immigration and resettlement with parenting a child with disability requires specificity in the types of services provided.

Leadership and Governance of health and social services is arguably one of the main building blocks of any health and social services systems (WHO, 2007), and is key a element for ensuring improved and effective services. The scope of this study did not allow for a critical review the macro-level policies; however, reports from international organizations such as WHO and UNICEF highlight the importance of the role of government in overseeing and guiding the whole health and social systems, private as well as public, in order to protect public interest (WHO, 2007). To ensure effective leadership and governance and to ensure quality of services, the government uses several mechanisms, for example, providing policy guidelines, ensuring oversight by use of intelligence on trends with a focus on equity, promoting collaboration across sectors within government and with actors in the private sector including civil society, strengthening systems' design by minimizing duplication and fragmentation, and ensuring all actors involved in service provision are held publicly accountable (WHO, 2007).

> *Policies at the provincial level can make a huge difference in kids' well-being (SP 23).*

Recommendation 1: Improve access to services – Use best practices to introduce key workers or case managers in the system.

For mothers of children with disabilities the responsibilities of care giving becomes more complicated because of the need for multiple services provided by a wide range of service providers and agencies dispersed in the city. Although the intentions of these services are to provide optimum medical services, social care, education, and emotional support to the children and their families, immigrant mothers can get "perplexed" by the bewildering number of contacts, appointments, paper work, and accessing these services (Carter & Thomas, 2011). Similar concerns were raised by the participants of our study. Many immigrant mothers, due to their limited knowledge of how services are organized in Canada, and in

> *A case management system would be incredibly effective, one which dealt with issues pertaining to schooling, health care, benefits available in the tax system (SP 1).*

some cases due to their limited English language skills, may encounter difficulties in access. Barriers can include: completing extensive paper work, finding out what services are available, limited or inaccessible transportation, and most importantly knowing who they should consult with if they needed help in a particular area.

These challenges are to a certain extent are recognized by the government and, as a result, initiatives such as early child development programs are in place. However, the current system fails to take a holistic picture of the needs of these children and their families and, as pointed out by study participants, the system lacks a single point of contact and co-ordination. Perhaps, as suggested by many study participants, a model may be built where a single service provider, such as a key worker or a case manager[7] would work with the mother to find the appropriate information and services and support her with paperwork and act as the family's main point of contact.

The evaluation results of intervention studies such as the Blackpool Early Support Pilot Program, which was one of the 45 Early Support Program Pathfinder projects implemented by the UK Government, was part of an initiative to improve the early support and care of disabled children in the UK (Carter & Thomas, 2011). In their evaluation, they found that much of the benefit accrued from strong, relational, and social-professional networking, which encouraged incorporating new ways of working into everyday practice. As a result the Department for Education of UK extended the successful approach up the age range (http://www.education.gov.uk/ childrenandyoungpeople/ send/improvingprovision/b00212060/early-support). Based on the lessons learnt from such studies, a Key Workers/Case Manager approach could be tested and implemented in our context.

> **Recommendation 2**: **Improve service by enhancing staff knowledge and skills through pre- and in-service training of all service providers, with emphasis on the importance of understanding the unique needs of families across cultures.**

The important role of service providers in early child development must be underscored in policy and programs. Service providers, such as child development and early intervention specialists, child care providers, welfare service providers, school teachers, health care professionals, educators and community based health caregivers should regularly upgrade their skills and knowledge on current trends and technologies through mandated pre-service and in-service trainings. All service providers must be trained and have the skills to provide client centered services. Studies conducted by the

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[7] A key worker is the person who coordinates, manages, and has a professional overview of a family's early support needs (Carter & Thomas, 2011).

Roeher Institute found that the health care system is not as well oriented to the needs of children with disabilities and their families as it is to others (Hanvey, 2002).

Mounting evidence indicates professionals who tend to over-medicalize and see disability as an individual problem tend to ignore structural issues that contribute to health status, such as poverty, discrimination/isolation and environmental barriers. "Doctors and other health professionals who encounter disabled people in their professional practice should be aware not only of the causes, consequences, and treatment of disabling health conditions, but also of the incorrect assumptions about disability that result from stigmatised views about people with disabilities that are common within society"(Shakespeare, Lezzoni, & Groce, 2009, p. 1816).

A formal investigation conducted by the Disability Rights Commission in the UK found that people with mental and intellectual disabilities received poorer service from health professionals resulting in higher rates of morbidity and mortality (Shakespeare, Lezzoni, & Groce, 2009). The report further recommends that service providers in health, education, welfare and other support services should be well trained and informed to be able to provide appropriate services and address the needs of diverse children and their families. Service providers should also be able to understand the importance of collaborative work and be skilled in working within interdisciplinary settings (Shakespeare, Lezzoni, & Groce, 2009). Our research results agree with these findings. Many participants commented that the service providers lacked comprehensive knowledge and understanding of the needs of children with disabilities which resulted in poor services.

> …[the school had labeled her [child with disability as a] *"sexual abuser against the teacher.… The school did this without looking at his diagnosis There was a .poor linkage between doctors, school and families…. These teachers are detached - there is no passion there (M 3).*

Another study, undertaken by the Canadian Council on Social Development, examined the quality of services in 112 diverse service organizations. The study describes poor services in the school system as one of the three most commonly stated unmet needs in the survey (Speziale & Carpenter, 2007). The report describes that children and youth with special needs are not being served adequately because of multiple barriers including inadequate funding, negative attitudes of some professionals, inaccessibility of facilities due to lack of transportation (Speziale & Carpenter, 2007). Hanvey (2002), in her discussion paper, highlights the results of Learning Disabilities Association of Canada. She notes that currently regular teachers are less likely to have the skills and knowledge required to meet the needs of students with learning disabilities in the class, and specific educational services for children with learning disabilities are less available.

The findings from previous studies and from our study emphasize the need for all service providers, and school educators in particular, to understand the intersection of immigration and cultural stereotypes, and have the appropriate knowledge and skills to address these issues when dealing with immigrant mothers of children with disabilities.

> **Recommendation 3**: **Ensure adequate funding is provided for effective delivery of social services either through government funds or through expansion of health and social insurance policies. However, to ensure equitable access of services, special funding allocations must be in place for disadvantaged and economically poor populations (e.g. children with disabilities within immigrant families).**

Children with disabilities come from diverse family backgrounds and live in families in different economic situations. However, children with disabilities are more likely to live in low income families as compared to other children (Hanvey, 2002; Hexem, Bosk, & Feudtner, 2011), and the probabilities are higher if they are in immigrant families. People living in poverty have less access to health services, and lower literacy levels (Hanvey, 2002). Moreover, parents of children with disabilities face additional costs related to disabilities such as cost of transportation, medications, equipment and home adaptations (Yantzi & Rosenberg, 2008). Hanvey (2002) highlights the results of a study carried out by the Learning Disabilities Association of Canada. She notes that only three percent of school-age children with learning disabilities receive special services from their schools while the rest are either unidentified or receive minimal service. She explains that due to a decrease in school funding over the years, the services at schools for children with disabilities have deteriorated over time.

Our findings are in alignment with previous research findings and suggest that many of the services did not have adequate funding which resulted in long wait times for services. Many mothers referred to the high costs of services and how excessive out-of-pocket cost was straining their household budget. They also expressed their frustrations of not having access to financial support, and as immigrants they felt they did not had enough financial resources to support their child to the level they would have liked.

> *It is very expensive to get services ... everything requires your time, your money; they take such a long time deciding. I still do not know if we will get it….. We have to sit and wait…. I want to know what is free (M 7).*

 Recommendation 4: **Improve inter- and cross-sectoral service coordination through appropriate legislation.**

A report from the Institute for Clinical and Evaluative Studies (Tu et al., 2005), pointed out that there is severe disconnect in the delivery of health services to children and youth, from the policy and decision making levels down to the provision of services. The report portrays a picture of a high degree of variation in services, limited information of the services to families, problems in service delivery and service utilization, duplication of services and challenges with integration of care (Ungar, 2004). These issues can only be expected to be more severe and more complicated as they pertain to families of children and youth with disabilities in general, and more specifically for immigrant families with children with disabilities. The complex and fragmented organization of the current child disability service system is making it difficult for mothers of children with disabilities to understand what benefits are available, how to access them, and how to piece together the various support services that best match their children's needs.

Mothers of children with disabilities usually require services from different sectors, such as health, education, social services, housing, and social benefits agencies including provincial disability supports which are themselves allocated across sectors. During the course of seeking services for their children, mothers encounter numerous contacts with different workers. However, one of the biggest hurdles pointed out by many participants of our study is the lack of co-ordination between the different agencies providing services to children with disabilities. The services are too dispersed and fragmented causing confusion and thus increased demands on mothers' time, energy, organizational and financial resources. Mothers in our study repeatedly spoke of ongoing struggle to find reliable information on what services are available, where and to whom to go to get appropriate services, and how to find transportation and service providers who could understand their situation and their needs. The current system also introduces inequities in accessing services among mothers of children with disabilities. To address these inequities strong interdisciplinary, cross-services bridges need to be built.

Lessons learnt from other countries and best practices could be adapted to our circumstances. To promote intersectoral linkages, the UK government passed legislation, the Children Act 2004, which mandates the establishment of local children's trusts to address the fragmentation of responsibilities for children's services. The legislation outlines a number of powers and duties to aid the establishment of children's trusts, including a broad power to pool budgets and a duty for agencies to cooperate (Polit & Beck, 2008).

> **Recommendation 5:** **Improve coordination between immigration and child welfare authorities so that immigrant mothers do not fall through gaps in law and policies.**

Immigration is increasingly recognized as being an important factor in child welfare according to Maiter, Stalker & Alaggia (2009) who are a group of Ontario child welfare scholars. Child welfare agencies can be a critical resource (Urquia et al., 2007) for immigrant families and can be an important source of social support for immigrant mothers. Social supports available through child welfare agencies may be emotional, instrumental or informational and can cross a broad spectrum. Maiter et al. (2009) make the suggestion that child welfare agencies advocate for the provision of more instrumental social supports, for example more accessible English as second language (ESL) classes and greater levels of support for immigrants seeking entry to the work force. In the case of immigrant mothers who live with extreme hardship and heavy stressors (Urquia et al., 2010), child welfare services may take on a heightened importance for mother and child well-being and safety. Our findings support theirs.

Among the many important goals of child welfare agencies is keeping children safe and in so doing keeping families together (Urquia et al., 2007). This latter goal, keeping families together, is one that is at times is challenged at the intersection of child welfare law and immigration law. Child welfare concerns and immigration issues may interact in a manner which gets in the way of this goal. The reality of this situation is not lost on immigrant mothers who have precarious status (such as sponsored wives and those in Canada without documentation) and who live with the fear of the enforcement of child welfare mandates and simultaneous enforcement of immigration.

In British Columbia the BC Law Foundation (http://www.lawfoundationbc.org/) along with the YMCA conducted important research which looked at the intersection in that province of family law and immigration law on single immigrant mothers without status and with children. What that research found was mothers were at risk of coming to the attention of authorities if they decided to leave an abusive relationship. The reason being they were not allowed to work to support themselves while waiting for determinations of their immigration matter and at the same time were unable to properly meet the material needs to their Canadian born children. Mothers were at risk of custody loss to abusive fathers in that study. We need similar studies across provinces and territories looking at gaps experienced by immigrant mothers in the setting of child welfare, family and immigration law.

Tier 2: Instrumental or meso-level support

> **Recommendation 6:** **Implement programs to raise public awareness and decrease stigma against children with disabilities.**

Participation and socialization of children with disabilities is greatly influenced by environmental and contextual factors. Inadequate knowledge about the trends, skills and knowledge about disabilities among children, youth and adults can adversely impact their attitudes toward children with disabilities. Evidence suggests that awareness programmes for children in school settings aimed to increase their knowledge and acceptance of disability are successful (Lindsay & McPherson, 2012; Van Lieshout, Cleverley, Jenkins, & Georgiades, 2011).

Many participants referred to the insensitive and disrespectful remarks made by some of the service providers, particularly within the school systems. Literature shows that many times the school's decision to include students with disabilities in regular classes 'inclusive education' is also influenced by race, language or socio-economic background of families (Canadian Coalition for the Rights of Children (CCRC), 1999). Other participants described being looked at differently by others in the community because they had a child with disabilities. Such negative perceptions, especially at the neighborhood level can have serious implications on mothers who may then go into social isolation.

To address these issues multiple communication channels including web portals can be used to deliver awareness programs to create positive attitudes and increase awareness among children, youth, service providers, and in the general population regarding the special needs of these children. Awareness programs can also address the issue of stigmatization and help build positive images of children with disabilities.

> **Recommendation 7:** **Help empower immigrant mothers of children with disabilities and to have social support programs informed by their lived experiences, actively involve mothers in the process of planning, program implementation and governance.**

Canada is a growing multicultural society and immigrants make up a large proportion of our urban population. According to Statistic Canada more than 75% of immigrants who have arrived in Canada since 2001 belong to visible minority groups, and the remaining 25% are of White/European descent (Statistics Canada, 2008a). Immigrant mothers who are experiencing challenges in accessing the system for their children with disabilities may have unique insights about their situation, of which researchers, policy makers and program planners are not aware. Therefore, in formulating and

implementing policies, laws, services, and programs, immigrant mothers of children with disabilities should be consulted and actively involved. This can be done by ensuring appropriate representation and active participation in all phases of education and health services design processes as an integral feature of right to health and education. The process of inclusion can empower immigrant mothers of children with disabilities and, thereby, help to further reduce health inequities and disparities. The WHO Commission on Social Determinants of Health emphasizes that inclusion and full participation in the society in which individuals settle is vital to the material, psychological, and political empowerment that form the basis for social well-being and equitable health (Commission on Social Determinants of Health, 2008). However, there is also a need to provide funding to educate and train mothers, to help them to develop the necesary skills to participate in senior administrative functions, and to train service providers to learn how to respect and work with mothers.

Tier 3: Emotional or micro-level support

Recommendation 8: **Ensure availability of respite care for mothers of children with disabilities to give them temporary relief and ease their daily caregiving burden.**

The importance of addressing the burden on caregivers of children with disabilities and the need for respite care must be underscored. Parents repeatedly report an urgent, unmet need for respite care, child care and household assistance (Petrenchik, 2008). Mothers in our study consistently referred to having no time to relax or to attend to their own needs. Other studies have ascribed increased level of stress and compromises in the functioning of caregivers of children with disabilities (Ertem, 2012; Ong et al., 1998). The findings from Ong and colleagues' (1998) study explain parenting stress could be modified by factors such as increased caregiving demands, low maternal education and having a minority ethnic background. The study further highlights the need for rehabilitation to be directed to easing the burden of daily care, among other issues.

Recommendation 9: **Incorporate evaluation of services given to mothers to assess whether they find them helpful to them and their families.**

Perceptive support, as a type of social support (House, 1981), is both experienced and theorized on a micro level while being interdependent with support given and received on macro and meso levels. Perceptive supports refers to the way individuals experience the adequacy and effectiveness of support they receive from their support systems. Thus, the judgments and impressions mothers of children with disabilities form influence the way they are able to cope with and respond to their many stressors. If they perceive the support they receive as positive, as helpful, their sense of empowerment is

heightened. Conversely, if their perceptions of support are inadequate or negative, they feel disempowered, making it more difficult to cope with their many caregiving stressors.

6.0   Study Limitations

The findings of this study should be considered in the context of certain limitations. First, as with any qualitative study the findings of this study may not be generalized to all mothers of children with disabilities because these mothers were selected from a limited geographical area and may not necessarily be representative of all mothers of children with disabilities in Canada. Different stories may emerge in other contexts depending on participants' background and their issues of concerns. However, the goal of this qualitative research was not to generalize findings, but to explore in-depth the experiences of mothers and generate knowledge and understanding about their lived experiences. Second, only mothers who had some comprehension of English language were included in this study, therefore the experiences of mothers who encounter severe language barriers were not captured. Third, the study did not include fathers' perspectives. Lastly, the study did not have a comparison group of Canadian born mothers to compare the results.

7.0   APPENDICES

Appendix 7.1 Definitions used in the report

#	Terminologies	Definition
1	Disability	As was defined by mother
2	ESL	English as second language
3	Service providers	Any professional who also deals with immigrant mothers and their children with disability
4	Region: South Asia	India, Pakistan, Sri Lanka and Afghanistan
5	Region: East Asia	China, Japan, Philippines, Taiwan
6	Region: Europe	England, Poland, Ukraine, Romania, Albania
7	SP	Service provider
8	M	Mothers

Mothers, we need your help!

This study is about

- Understanding perceptions of social support among **immigrant mothers of children with disabilities**
- Discovering ways to **improve services and supports** for mothers of children with disabilities

We would like to hear from you if

- You have one or more children with a disability or disabilities
- You have immigrated to Canada

We will offer you

- A chance to speak out and inform practice and policy recommendations

- An opportunity to learn about available resources for parents of children with disabilities

- An honorarium of $30 for the interview

To participate in the study please call

Sheila Jennings, Project Coordinator

Phone: 416-736-2100 Ext 44527

Email: sheilaki@yorku.ca

7.3 Study participants report feedback form

Date:_____

We Value Your Input and Feedback on the Draft Report

Dear Colleagues and partners of the Mothers Project, we would very much like to have your valuable comments and feedback to help improve and finalize this draft report. Please be precise (due to the number of individuals we are seeking input from) **and return the completed form by _____** *to* owhchair@yorku.ca Please include in the **Subject: Feedback Mothers Project**

1) **Would you like your name to be listed/acknowledged in the report?** ⬚Y ⬚N
   (Note: We will not identify your identity in any section of the report itself)

2) **Would you like your organization's name to be listed in the report?** ⬚Y ⬚N

3) **List 2 important points that we have missed in this report.**

4) **Briefly describe 1 point that you dislike about this report and would suggest to be changed. Please be very specific and indicate the page number (pg. #).**

5) Briefly describe <u>1</u> point that you like about this report.

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6) Would you say the recommendations are comprehensive? If not please make specific comments.

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7) Please add any other observations or comments you would like to make.

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ABOUT THE RESEARCH REPORT

This research report is based on a community based qualitative study undertaken by the Office of Women Health Research in Mental Health, York University. The project was funded by the Faculty of Health through the Principal Investigator (N. Khanlou, PIs Start-Up funding).

The study explores the challenges and facilitators that immigrant mothers living in the Greater Toronto Area encounter in accessing services for their children with disabilities. By capturing the lived experiences of the mothers and by understanding the perspectives of service providers, we can help inform inclusive and relevant policy and program recommendation, and advocate for inclusive and evidence-based policy and program recommendations for better social support for mothers. As part of this project, we have produced three project Information Sheets that include detailed research findings analysis (http://nkhanlou.info.yorku.ca/knowledge-transfer/publications/).

WOMEN'S HEALTH RESEARCH CHAIR IN MENTAL HEALTH

The Office of Women's Health Research Chair in Mental Health is part of the Faculty of the Health at York University. We are interested in studying social factors that affect the mental health and wellbeing of women, youth, and children. To learn more about the activities of the Office, please visit   http://nkhanlou.info.yorku.ca/

ABOUT THE RESEARCHERS

Dr. Nazilla Khanlou is an Associate Professor at York University and the Principal Investigator of this study. Sheila Jennings is a PhD Candidate in law at York University and was the Coordinator of the Mothers Project. She conducted all the interviews for this project. Other team members include Dr. Nasim Haque, Dr. Deborah Davidson, Dr. Mahdieh Dastjerdi, Alexis Buettgen, and Wajma Soroor. For detailed information on the entire team, please visit http://nkhanlou.info.yorku.ca/research/community-based/

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