A Narrative Inquiry:
Experiences of Iranian Mothers of Children with Disabilities in Toronto, Ontario

by

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ABSTRACT

Using a narrative inquiry approach, this study examines the life narratives of seven women who emigrated from Iran and have a child who has a disability. Influenced by a social constructivist epistemology, this inquiry honours the mothers' voices and applies a developmental lens to the analysis of their experiences.

To analyze the data, two complementary analytic approaches were used: categorization and contextualization. Through categorization, the narratives were divided into themes that included interpreting and internalizing motherhood, managing systems of support, and success through education. Through contextualization, restoried accounts of the seven narratives were created to allow the author to situate them within context. Overall, the analyses indicated that the women's experiences of responsibility, blame and stigma often isolated them and reduced the availability of emotional support. They also highlighted the accessibility of typical professional settings, such as schools and hospitals as original sources of professional support. Finally, the value placed on education and the women's initiative in creating their own sources of support emphasizes the need for culturally relevant opportunities for self-determined advancement and education. The experiences of immigrant women who have a child with a disability are not well understood. This study gives voice to the perspectives of a subset of such women, so health and community programs can begin to be sensitized to their needs.

RESUME

La présente étude, utilisant l'enquête narrative, examine le compte rendu narratif du quotidien de sept femmes ayant émigré de l'Iran et qui ont un enfant présentant une déficience. Influencée par une épistémologie socio-constructiviste, cette enquête fait une large part à la voix de ces mères et analyse leur expérience d'un point de vue développemental.

Pour étudier les données, deux approches analytiques complémentaires ont été utilisées : la catégorisation et la contextualisation. En ce qui concerne la catégorisation, les récits narratifs ont été répartis par thèmes tel que l'interprétation du rôle de la mère, la gestion des systèmes de soutien et la réussite par le biais de l'éducation. Pour la contextualisation, l'auteur a produit des comptes rendus en « retravaillant » les sept récits afin de les situer en contexte. De façon générale, les analyses ont indiqué que les sentiments de responsabilité, de blâme et de stigmatisation éprouvés par ces femmes ont souvent contribué à leur isolement, diminuant du fait même l'accès à un soutien émotif. Les analyses montrent également les services professionnels typiques, comme les écoles et les hôpitaux, comme sources de soutien professionnel aux mères questionnées. Finalement, l'importance que ces femmes attachent à l'éducation et les initiatives qu'elles prennent pour développer leurs propres sources de soutien montrent qu'il existe un réel besoin en matière de développement personnel et de formation adaptés culturellement. De façon globale, les expériences des femmes immigrantes ayant un enfant qui présente une déficience restent mal comprises. En leur donnant la parole, la présente étude tente de sensibiliser les chercheurs et les responsables des programmes de santé et des programmes communautaires aux besoins de ces femmes.

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CHAPTER ONE: INTRODUCTION

This dissertation highlights the life narratives of seven women who emigrated from Iran to Toronto, Ontario and had a child with a disability. The purpose of the study was to use a narrative inquiry and honour the voices of a group of women at the intersection of immigration, motherhood and disability. Using Bronfenbrenner's Person, Process, Context and Time theory (Bronfenbrenner & Morris, 2006), a developmental lens was applied throughout the process of data collection and analysis. The profile of immigrants with disabilities in Canada is not well understood. This thesis provides insight into the experiences of a subset of this population and can serve as a starting point for researchers and practitioners to become better informed about their needs.

Structure of the Thesis

This thesis is presented in five chapters. Chapter one outlines the relevance of the study and introduces the research questions that guide the inquiry. Chapter two is a literature review that provides a context for the narrative, and chapter three outlines the methodological, ontological and epistemological positioning of the inquiry. The fourth chapter is the 'narrative analysis' and includes two distinct sections; the first segment comprises excerpts from the stories (translated from Farsi) of seven Iranian immigrant mothers who have a child with a disability. In the second section, the data were fragmented to draw out themes that articulated common experiences of emigration from Iran, motherhood and disability. In keeping with a narrative paradigm, chapters three and four are written in a personal voice. In chapter three, a personal voice is used to address in detail how the researcher is situated within the research while chapter four highlights the stories described by the women. The researcher's perspective is necessary not only because it allows the reader insight into how personal experiences have influenced the research process, but also because it provides a basis for the selection of the research methodology.

Chapters two and five, the literature review and discussion, provide context for the study and are written in a formal academic tone. Chapter five begins with a discussion of how the stories and major themes that emerged from the narratives fit in with the current literature. The chapter ends with a description of the significance of the study and with recommendations for further research, policy and practice.

Relevance of Study

This inquiry aims to examine the complexities of Iranian women's lives and, in particular, to explore the experiences of immigrant Iranian mothers who have a child with a disability in Toronto, Ontario, Canada. Over the past decade across North America, there has been a significant surge in immigration rates, and Canada has developed a reputation as the country of immigrants (Biles, Tolley, & Ibrahim, 2005). Recently, immigration has been the most important component of Canada's population growth; in the five years between 2006 and 2011, approximately 1.2 million foreign-born people immigrated to Canada (Employment and Social Development Canada, 2013). Individuals who migrate to a new country typically undergo cultural change, a process known as acculturation, which has been found to result in psychological stress marked by a reduction in their physical and mental states (Nwadiora & McAdoo, 1996). Acculturation was first described by Redfield, Linton and Herskovits (1936) as the phenomena that results when groups of individuals with different cultures come into continuous first-hand contact resulting in subsequent changes in the original cultural patterns of either or both groups (p. 149). There has been significant research done on the acculturation process since the time it was first described (Berry, 1997; Cohen, 2011; Kim, 2011). Through this process individuals may experience the loss of their previous familiar social structure and culture, which can cause a grief reaction. Contrasts between the cultures can be experienced by the individual or group that may be construed as a form of rejection of their culture of origin and expressed as deculturation, the experience of alienation from and loss of cultural identity (Bhugra, 2004). Many children are faced with this experience of deculturation when they enter formal schooling. Studies show that the loss of the first language occurs rather quickly following immigration for most children (Turcotte, 2006). This is largely viewed in a positive light as Canadian schools and daycare centres prefer that children learn English or French as quickly as possible (Egbo, 2009). In response, immigrant children may diminish the value of their home language and may come to believe that it has little or no role to play in the process of accomplishing goals in Canadian society (Bernhard & Freire, 1999).

These studies of acculturation and deculturation widely acknowledge that individual and environmental factors impact these complex processes. Studies have found that various factors, such as immigrant status, generation, family role, country of origin, linguistic group, age at arrival, socioeconomic status and sex impact an individuals' experiences of acculturation (Berry & Sabatier, 2010; Ataca & Berry, 2002; Kwak & Berry, 2001; McDonald & Worswick, 2012). In addition to individual factors, the degree to which the host country welcomes cultural diversity will impact experiences of immigrants. For example, Canada prides itself on being a cultural mosaic, while the assimilationist ideology of the United States can be described as a cultural melting pot in which immigrants are expected to adopt and follow American norms (Alba & Nee, 2003; Portes & Rumbaut, 1996). The main assertion behind a cultural mosaic is that the country as a whole becomes stronger with the cultural diversity of immigrants. As a concrete example of the mosaic in Canada, Pierre Elliot Trudeau's government adopted the policy of Multiculturalism within a Bilingual Framework (1971) in Canada. The idea behind the policy was that while Canada had two official languages, it had no official culture (Haque, 2005). Although the policy of multiculturalism has been widely criticized, its adoption denoted a shift from an assimilationist ideology, similar to that applied by the United States to a pluralistic ideal (Egbo, 2009). The migration experiences of individuals to Canada depend on a wide range of factors, including the immigrant's country of origin, their knowledge of Canada's official languages, and the policies of the jurisdiction in which they settle.

Iranians are a fast-growing migrant community in Canada and have increased 147% between 1996-2006; in 2011, Iranian permanent residents accounted for the 4th greatest number of permanent residents immigrating to Canada (Statistics Canada, 2013). According to 2001 census data, the majority of Iranians (58%) settled in Ontario, 25% in British Columbia, and 11% in Québec. Of the Iranians who settled in Ontario the majority, 78%, made their homes in Toronto, the largest metropolitan city in Ontario (Garousi, 2005). Due to the large number of Iranians living in Toronto, a profile and needs assessment was conducted in 1999 to determine the contributions and challenges faced by Iranians during the acculturation process (Dilmaghani, 1999). More recently, a few studies have supplemented this analysis by assessing the demographics and economic and professional profiles of Iranians living in Toronto (Dastjerdi, 2012;

Garousi, 2005). According to these studies, some of the greatest contributions of Iranians to the city of Toronto are their professional expertise and their high levels of education (Dilmaghani, 1999; Garousi, 2005). Dilmaghani (1999) found that just prior to the 21st century, over 50% of migrants from Iran had degrees in higher education, with 49% of women and 58% of Iranian men obtaining undergraduate or graduate degrees prior to immigration.

According to recent data, newcomers settling in Ontario are faced with a number of key challenges including finding employment and affordable housing, language difficulties, and access to education. Individual factors might exacerbate or add to these challenges, especially when service providers in Ontario are not adequately equipped or informed of how to meet the needs of population. For example, recent efforts have been made in Ontario to determine the specific needs of newcomers with disabilities to ensure service providers are adequately meeting their needs. Disability can be defined by social and medical models. According to medical models, disability can be described as any degree of physical disability, infirmity, malformation or disfigurement, a condition of mental impairment or a developmental disability, a learning disability, or a dysfunction in one or more of the processes involved in understanding or using symbols or spoken language, or a mental disorder (Ontario Human Rights Commission, 2014). By contrast, the social model of disability was first described in 1983 as “a switch away from focusing on the physical limitations of particular individuals to the way the physical and social environments impose limitations on certain groups or categories of people.” (Oliver, 1983, p. 23)

Findings suggest that immigrants with disabilities experience social and environmental barriers in the settlement process such as challenges in their interactions with settlement workers, due to a lack of disability-related accommodations in ESL classes, inaccessible temporary housing, welcoming centres or shelters. Newcomers may also minimize their needs, fearing exclusion or deportation (Welcoming & Inclusive Communities Accessibility Project, 2011). The passing of the Accessibility for Ontarians with Disabilities Act (AODA, 2005) and standards set by the Ontario Council of Agencies Serving Immigrants (OCASI) and the Ethno-Racial People with Disabilities Coalition of Ontario (ERDCO) have been working to improve access to settlement services for immigrants with disabilities.

Despite recent attempts to better understand the experiences of immigrants with disabilities and to incorporate improvements to settlement services, data on individuals migrating from Iran are scarce. Previous studies of Iranian migrants to Canada have largely focused on more global challenges with access to general health care (Dastjerdi, 2012; Dastjerdi, Olson, & Ogilvie, 2012). There are a number of plausible reasons for the absence of disability as a stated challenge in the categories created and presented in previous studies of Iranian immigrants with disabilities. The first explanation is that, as noted, Iranian immigration has increased in recent years and earlier studies of this phenomenon do not reflect the current population. A second explanation is that Canada's immigration policies have removed explicit race restrictions and appear to be inclusive, however, there are limitations in the selection of "desirable immigrants". For example, the Immigration and Refugee Protection Act (2001) includes an excessive demand cost threshold excluding immigration for applicants with disabilities. This restriction includes the applicants themselves, as well as any member of their family. As a result, individuals with disabilities would not have immigrated to Canada, or, if they had, they would not disclose a disability status for fear of deportation. A third possible reason is the long-standing stigma associated with major illness or disability in Iran (Khodabakhshi Koolaee & Etemadi, 2010; Samadi, 2008). Iranian families may fear exclusion from their new and existing communities during the acculturation process, and may not communicate a child who has an illness or disability avoid stigmatization from friends and family who are uninformed about the condition (Kodabakhshi Koolaee & Etemadi, 2010).

The level of stigma and stress experienced by parents who have a child with a disability has been found to disproportionately impact mothers (Dabrowska & Pisula 2010; Davis & Carter, 2008). The high levels of stress experienced by the mothers is not surprising given that the responsibility of child-rearing and the blame associated with any challenge that impacts the child has been traditionally attributed to mothers. A sampling of the social science literature on mothers and health care professionals demonstrates that mothers with children with disabilities continue to be pathologized as over-protective, difficult, unrealistic or in denial of their children’s disabilities (McKeever & Miller, 2004). Practitioners, particularly psychiatrists, have also traditionally blamed mothers for causing their child’s illness or disability (Ladd-Taylor & Umansky, 1998; Singh, 2002). This trend continues within Iranian society, where mothers are presumed to be the main caregivers and the responsibility for care and child rearing falls with women (Kermanshahi, Vanaki, Ahmadi & Azadfalah, 2009; Khodabakhshi Koolaee & Etemadi, 2010). While recent studies have attempted to shed light on the experiences of Iranian mothers raising children with disabilities, these studies are mainly set in Iran

(Kermanshahi et al., 2008; Kermanshahi et al., 2009) and have not addressed the needs or challenges associated with displacement or migration.

My own background as an Iranian woman permitted me to conduct interviews with other Iranian women with relative ease as I was able to understand and interpret non-verbal cultural cues associated with verbal communication. I also had the benefit of speaking with recent immigrants who may not speak English or French without the need for an interpreter or translator.

Given that the research topic is novel and unexplored, I chose to use qualitative methodologies as they permitted me to explore the richness of experiences among a select few participants (Creswell, 2007). By using a narrative approach, the participants' own experiences guided the research process, analysis, and the conclusions.

Ultimately, the goal of this dissertation is to explore the experiences of Iranian immigrant mothers who have a child with a disability in Toronto, Ontario, Canada, by honoring their voices and by acknowledging their contributions as producers of knowledge. Narrative interviews were conducted to explore the mothers' experiences with formal and informal support systems and with accessing disability services in Canada. As this topic is largely unchartered territory, the research questions are considered to be exploratory (Creswell, 2007).

Research Questions

Central question. There is one central question that guided the research design and analysis:

What are the experiences of immigrant mothers in relation to accessing disability-related supports and services for their child(ren) since emigrating from Iran to Toronto, Ontario?

Sub-questions. The following procedural questions were used as probes during the interview process with Iranian mothers living in Toronto with a child diagnosed with a disability.

- What are the experiences of Iranian mothers who have a child with a disability in Iran?
- What stories can be told from the experiences during the immigration process to Toronto, ON?
- What are the experiences of Iranian mothers who have children with disabilities upon immigration to Toronto?

CHAPTER TWO: LITERATURE REVIEW

Divided into three broad sections, this literature review provides the overall context for the study. As the literature on immigration of Iranians to Canada in association with disability is scarce, the review will cover four sections that provide the framework for the research questions. The first section covers an overview of relevant immigration policies, including the history of immigration to Canada, current policies, the immigration of Iranians to Canada and Toronto, Ontario. The second section addresses the demographics of the participants in the study, beginning with characteristics of Iranians living in Canada, and later addressing the population of Iranian women in Canada. The third section addresses issues pertaining to disability including the experiences of individuals with disabilities in Iran, disability-related exclusions in immigration policies, and challenges with accessibility of resources for newcomers with disabilities in Canada. The fourth and final section provides an overview of Bronfenbrenner's Person-Process-Context-Time (PPCT) theory (Bronfenbrenner & Morris, 2006), the theoretical framework that frames the methodology and analysis of this dissertation.

Immigration to Canada

Before examining the experiences of Iranian mothers who have a disability in Canada, it is important to consider how immigration policies contributed to shaping the experiences of this population. The following section will include the history of immigration to Canada, current Canadian immigration policies, Immigration of Iranians to Canada, and more specifically, the immigration of Iranians to Toronto, Ontario.

History. Immigration became a priority of the Canadian federal government following confederation in 1867 with the intent to use immigration to populate regions and to strengthen the economy (Albanese, 2009; Kelley & Trebilcock, 1998). Early policies were restrictive; immigrants of Caucasian decent were sought while those from Southern Europe, South and East Asia, South America and Africa were banned or discouraged (Albanese, 2009). Racial discrimination fluctuated depending on the country's economic needs as well as the social and political climate following the First and Second World War. It was not until after 1962 that the Canadian government revised the immigration regulations and seemingly removed explicit restrictions to immigration based on ethnicity and race. These changes to immigration regulations resulted in a change in the demographics of immigrants to Canada, with non-European immigrants increasing the ethnic diversity in the country (Albanese, 2009; Kelley & Trebilcock, 1998).

Current immigration policies. Today the law set to guide Canada's immigration is known as the Immigration and Refugee Protection Act (2001) and claims to have four major goals: to develop a strong and prosperous Canadian economy, to reunite families, to fulfill Canada's international legal obligations, and to protect the health, safety and security of Canadians (Immigration and Refugee Protection Act, S.C. 2001, c.27).

Canada admits approximately 250,000 permanent residents each year that can be divided into the following categories: economic class, family class, or humanitarian/refugee class (Citizenship and Immigration Canada, 2011). Those who qualify under economic class are typically skilled or business immigrants, while individuals admitted under family class are specified as family members and adopted children. Refugees, and others not falling into these categories qualify for entry on humanitarian or compassionate grounds or for reasons related to public policy. A merit point system was developed by 1976 in lieu of explicit race restrictions and is now accorded to determine which immigrants are most suitable for entry. As noted on the Citizenship and Immigration Canada website (Citizenship and Immigration Canada, 2010), merit points are accorded to six selection criteria for immigration applicants in the independent and sponsored classes: education, language ability in English and/or French, applicant's age, work experience, arranged employment, and adaptability (which includes having close relatives in Canada). The needs of the Canadian demographic and labour market continue to influence who is granted entry to Canada, and the merit system is modified in such a way to fit the prospective immigrants as closely as possible to the Canada's needs (Isajiw, 1999). For example, since 2008, changes have been made to immigration policies to focus on economic class immigrants who have the skills and abilities to contribute to Canada's economy (Alboim & Cohl, 2012).

Although the merit point system is applied consistently throughout the country, individual provinces work in collaboration with the federal government to fulfill their own unique economic and social labour market needs (Hawkins, 1988). The degree to which each province has ownership over its own policies, varies. For example, the *Canada-Québec Accord* (1991) gives Québec the power to set its own admissions and to choose foreign nationals. In the 1960s Québec established its own department of immigration to protect the French language and it's own distinct cultural heritage, and has since negotiated agreements with the Government of Canada regarding immigration policy, criteria, and targets (Alboim & Cohl, 2012).

Today, immigration policies are relevant for an increasing number of people as there continues to be a surge in immigration rates to Canada, with nearly 2,155,000 immigrants making Canada their home between 2001-2011, and with more than half of this number representing immigration between 2006-2011 (Citizenship and Immigration Canada, 2011). According to the 2011 National Household Survey, 20.6% of the total population was foreign-born, a slight increase from the 19.8% in the 2006 Census (Statistics Canada, 2011). Canada has seen the largest growth among G8 nations, with an overall population growth of 5.4% between 2001 and 2006 (Ontario Ministry of Finance, 2006). Among the countries in the Organization for Economic Co-operation and Development, Canada along with Australia, the United States, and New Zealand, ranks as a major immigrant-receiving country (Citizenship and Immigration Canada, 2005). According to a Statistics Canada fact sheet published in and detailing immigration trends in 2008, 45.6%, of immigrants emigrated from Asia and the Pacific, 21.7% emigrating from Africa and the Middle East, 17.4% from Europe and the United Kingdom, and 15.3% from South and Central America and the United States combined. These changes in the visible diversity of the country in conjunction with the overall increase of immigration rates have led to changes in Canadian policies that highlight integration as a goal of a multicultural society. In particular, in 1971 Canada was the first country to develop an official Multicultural Policy in order to eliminate barriers between minority and dominant groups (Nasrallah, 2005).

Iranians immigrating to Canada. The number of Iranian-Canadians living in Canada has increased significantly in recent history. In the ten years following the 1979 Iranian revolution, the percentage of Iranians immigrating to Canada has quadrupled, from under five thousand to approximately 20,000 inhabitants (Dilmaghani, 1999; Garousi, 2005). According to a 2011 National household survey, 125,825 Iranian-born Canadian citizens reside in Canada (Statistics Canada, 2013).

Immigration to Canada increased slightly in 1971 and exponentially by 1991, with very little immigration prior to 1961 (Garousi, 2005). Although few Iranians immigrated to Canada from 1950-1979, a significant number of people emigrated from Iran to the United States, United Kingdom, West Germany, France, Austria and Italy. Iranian emigrants were predominantly youth sent abroad for education as well as religious minorities such as Bahai's, Armenians, and Jewish-Iranians who fled the country in anticipation of persecution by the post-revolution regime (Hakimzadeh, 2006). Shortly prior to the Iranian revolution, in 1976, Canada's immigration policies had removed race restrictions and introduced a merit point system, which increased the number of professionals and academics entering the country (Garousi, 2005; Hakimzadeh, 2006). These changes in immigration policies aligned with the post-revolution era in Iran, which brought about changes, including mandating women to wear the veil, decreasing educational opportunities, and mandating military service for young men recruited for the Iran/Iraq war (Garousi, 2005; Hakimzadeh, 2006; Shahidian, 1999). Families with young women escaped rigid gender confines, young men escaped military service, and a large number of the country's most skilled and educated professionals, entrepreneurs, and academics fled Iran for better opportunities in another country. Most recently, similar trends of emigration have continued with highly skilled individuals leaving Iranian universities and research institutions for Canadian ones (Hakimzadeh, 2006). The majority of these immigrants make their home in Toronto, Ontario, the most multicultural province in Canada.

Iranian immigration to Toronto, Ontario. Ontario is the most populated province in Canada (Statistics Canada, 2013) and is home to more than half of Canada's immigrant population ("Ontario Immigration", n.d.). The two provinces with the largest percentage of people born outside the country were Ontario, with approximately 3,611,400 immigrants (or 53.3%), and British Columbia, with approximately 1,191,900 immigrants (or 17.6%). Of the 3, 611, 400 immigrants currently in Ontario, approximately 72,140 are Iranian-born immigrants who have assumed Canadian citizenship (Statistics Canada, 2013).

The capital of the province of Ontario is the city of Toronto where more than 150 languages are spoken every day and 50% of residents are born outside of Canada ("Ontario Immigration", n.d.). Of the 121,510 documented Iranians living in Canada, over 55000 have made their home in the greater Toronto area and over 6,000 of those are in the city of Toronto alone ("U Reach Toronto", 2014). There are a host of services available to new Iranian immigrants to Toronto, Ontario with online resources pointing individuals to community resources (Burr, 2011; "Immigration Portal", n.d.; "Local Immigration Partnership", 2014; "Newcomers Toronto Fair", 2014). The resources provide information on how to navigate various employment, education, and health care systems ("Local-Immigration Partnership", 2014; Newcomer Strategy Initiative, 2013). In some cases, these services are available in numerous languages including Farsi. Despite the availability of online resources and of Farsi-speaking service providers, there are a number of barriers to access to services for Iranians in the greater Toronto area. These include a lack of knowledge about and a distrust of the Canadian health care system, fear of disclosure, anxiety, and unmet needs for psychological support (Dastjerdi, 2012). A study of Iranian immigrant access to Canadian health care services in Edmonton, Alberta found that Iranians independently sought health care services by making use of the public library system and the Internet (Dastjerdi, 2007).

A Profile of Iranian Female Immigrants in Canada

The ways in which individuals adjust to a new cultural environment following immigration depends on a host of factors that include country of origin and gender. The following section will address how the profile of the individuals in the study, as females and migrants from Iran, impacted their experiences of immigration and acculturation.

Iranian immigrants in Canada. Despite changes in Canadian immigration policies over time that have removed race as a criteria for immigration, Canadian immigration policies continue to be restricting (Albanese, 2009). Current policies welcome highly skilled and educated individuals who not only fill the economic need at a point in time, but also bring expertise and experience to Canada. According to 2006 census data (Statistics Canada, 2006), the proportion of recent immigrants with a university degree was twice as high among immigrants than among native-born Canadians.

Despite the high level of schooling of recent immigrants, they have difficulty entering the Canadian labour market and are often underemployed or unemployed (Frenette & Morissette, 2005; Picot & Hou, 2003; Statistics Canada, 2008). In 2006, 28% of recent immigrant men and 40% of women with university degrees held employment with low educational requirements compared with 10% and 12% of native-born Canadians. According to Iranian immigrants, this pattern of unemployment and underemployment is a main source of stress in their lives post-migration (Dilmaghani, 1999). The disparity between education and employment has increased significantly since 1991, and can be partially attributed to the low rate of recognition of foreign credentials (Dilmaghani, 1999; Ferrer & Riddell, 2008; Green & Worswick, 2012). Studies suggest that a lack of recognition of foreign credentials might not be the only factor impacting the underemployment of immigrant groups (Dilmaghani, 1999; Galarneau & Morissette, 2008). In addition to educational attainment, work experience acquired in foreign countries is not always recognized in the Canadian labour market (Aydemir & Skuterud, 2008; Ferrer & Riddell, 2002; Green & Worswick, 2012; Picot & Sweetman, 2005).

Difficulties obtaining employment are often compounded by challenges with adjustment to the host culture, which can lead to a number of difficult emotional outcomes for Iranian immigrants such as feelings of frustration, depression, and extreme stress (Bagheri, 1992; Dilmaghani, 1999, 2001; Emami, Benner, & Ekman, 2001). Consequently, immigrants are disproportionately poorer (Hyman, 2004) and are at a greater risk for mental illness (Sue & Sue, 2003) compared to the general population. The successful integration of immigrants into their host country is possible, but depends on a series of personal and environmental factors, such as knowledge of the host-country's language and the availability of environmental supports (Citizenship and Immigration Canada, 2011).

Iranian women in Canada. In order to better understand the experiences of Iranian women in Canada, it is essential to first recognize the parameters of their lives prior to migration. Today, the Constitution of the Islamic Republic of Iran emphasizes a woman's responsibility for motherhood and stresses that the role of a woman is to create a solid family unit that will be the basis of society, with a focus for the growth and elevation of mankind (Iran Chamber Society, 2014). Although constitutionally, women in Iran are valued predominantly in terms of their obligations within the family, attempts to restrict their functions under the law were unsuccessful. Iranian women rejected traditionalist values by attaining high literacy and education rates, and by becoming increasingly engaged in social and economic activities (Rezai-Rashti & Moghadam, 2011). According to recent statistics, women comprise approximately 63 percent of students admitted to universities in Iran and push to be recognized as rights-bearing citizens in Iranian family courts (Osanloo, 2009). However, success in legal and education domains have not translated into greater employment opportunities for educated women; in 2004, nearly 20% of Iranian women with degrees in higher education were unemployed compared to 7% of Iranian men (Rezai-Rashti, 2011).

The high rates of education and underemployment among Iranian women in Iran are similar to trends in Canada; Dilmaghani (1999) found that just prior to the 21st century, over 50% of migrants from Iran had degrees in higher education, with 49% of women and 58% of Iranian men obtaining undergraduate or graduate degrees prior to immigration. However, similar to Iran, high levels of education did not equate to greater employment opportunities post migration for both men and women; a trend of high education and underemployment continues in both Iranian and non-Iranian immigrant communities today (Frenette & Morissette, 2005; Picot & Hou, 2003; Statistics Canada, 2008). Within the Iranian community in Toronto, Dilmaghani (1999) found that males and females use differing coping mechanisms to deal with the stress of unemployment.

While males reported using drugs and alcohol and exercising as a form of stress release, women noted that having a strong support network of friends and family helped them through life's challenges. Not surprisingly, the women also described the lack of such an emotional network in Canada as isolating, and a significant barrier in their adjustment.

Disability

Feelings of isolation experienced by Iranian women in Toronto may be exacerbated when a member of the family is diagnosed with a disability. Mothers of children with disabilities in Iran reported being pushed away and stigmatized by friends and family who were uninformed about their child's condition (Kodabakhshi Koolaee & Etemadi, 2010). The following section will highlight the ways in which disability could have impacted the experiences of the participants in the study. The section begins with conceptions of disability in Iran, limitations experienced by individuals with disabilities through the immigration process, conceptions of disability in Canada, and factors impacting access to disability-support services in Canada. As the literature on access to services for Iranian immigrants with disabilities in Canada is scarce, the review will cover how Iranians have accessed general health care services immediately following immigration.

Conceptions of disability in Iran. The history of disability rights in Iran has been tumultuous and like many countries, Iran has faced challenges in creating a definition of disability that results in rights and benefits (Moore & Kornblet, 2011). The State Welfare Organization, the branch of government that provides welfare services to those who qualify in Iran defines disability under four categories: physical, hearing, visual, and mental (Moore & Kornblet, 2011). Despite significant stigma associated with disability in Iran there have been significant changes in the lives of Iranians with disabilities over the past 100 years. Educational opportunities emerged in the 20th century with a number of non-governmental organizations and charities whose mandate was to provide education to students with visual and hearing impairments and intellectual disabilities (Kako-Joibari, 2003; Samadi, 2008; The Iranian Special Education Organization, 2006). In 1968, the Iranian Ministry of Education took legal steps to acknowledge the educational needs of students with disabilities by establishing a dedicated education bureau (Samadi, 2008; Kako-Joibari, 2003). Shortly thereafter, immediately following the Iranian revolution (1979), The Iranian Special Education Organization (ISEO), an organization affiliated with the ministry of education, was established to address the needs of a growing population of individuals with disabilities in Iran (Kako-Joibari, 2003). Since this time, various groups of students with physical and sensory disabilities have been successfully integrated in mainstream schools (Adibsereshki, Tajrishi' & Mirzamani, 2010; Adibsereshki & Salehpour, 2012). Despite the move towards more inclusive practices in education, families continue to report a lack of support from professionals in the health and education domains. Specifically they require more adequate information about their disabled children, support in managing their children's difficulties, and discussions of future opportunities (Kermanshahi et al., 2009). On a grassroots level, parents have been working to establish their own sources of support through parent organizations that advocate for the rights of their children with disabilities (Samadi, 2008). These efforts are supported by research initiatives that work to enhance the quality of life of Iranians with disabilities living in Iran (Sajedi, Alizad, Alaeddini, Fatemi, & Mazaherinezhad, 2008; Samadi, 2008; Kermanshahi et al., 2009).

Recent studies suggest that having a child with a disability that in addition to the difficulties families face in receiving adequate professional support, they also face challenges in their personal interactions with friends and Families. Parents in Iran indicate that having a child with a disability in the family elicits pity from friends and family and isolates the family (Kermanshahi et al., 2009; Samadi, 2008).

Immigration and disability. The challenges faced by Iranians with disabilities are not limited to their time in Iran. This population can face additional difficulties in the process of immigration to a new country and during the settlement process. As previously noted, Canada's economic needs have traditionally driven the country's immigration policies (Isajiw, 1999; Palmer, 2002). These economic motivations are of central importance and have contributed to creating the preferred and non-preferred categories that impact the selection of immigrants (Palmer, 2002). In addition to merit points used as immigrant selection criteria, there are a number of reasons applicants can be found inadmissible and denied a visa. Health status is a common reason that applications are denied entry to Canada. The Immigration and Refugee Protection Act (2001) includes an excessive demand cost threshold that is used to determine whether a foreign national should be barred from Canada based on health status. The threshold is most frequently applied when considering the admissibility of foreign nationals who are seeking permanent residence in Canada. According to Clause 38 (1)(c) of the Immigration and Refugee Protection Act, the term excessive demand can be described as:

> a) A demand on health services or social services for which the anticipated costs would likely exceed average Canadian per capita health services and social services costs over a period of five consecutive years immediately following the

> most recent medical examination required by the IRPR, unless there is evidence that significant costs are likely to be incurred beyond that period, in which case the period is no more than ten consecutive years; or
>
> b) A demand on health services or social services that would add to existing waiting lists and would increase the rate of mortality and morbidity in Canada as a result of an inability to provide timely services to Canadian citizens or permanent resident. (Immigration and Refugee Protection Act, S.C. 2001, c.27)

Evidently, people with disabilities are considered as economic burdens and are excluded and marginalized during the immigration process (ERDCO, 2005). There are countless cases of individuals who have been denied access to the country or who have been deported due to the disability of a family member (Council of Canadians with Disabilities, 2011). As a case example, in April 2011, the Barlagne family in Montreal was fighting to stay in Canada when they were faced with deportation because of the disability of their daughter. Immigration Canada opposed paying $5,259 per year for the child's education citing economic burden and the family was ordered to leave Montreal. The Barlagne family is not alone in their experience (Council of Canadians with Disabilities, 2011).

Slight changes have been made to the Immigration Act through the advocacy of groups such as the Council of Canadians with Disabilities. Through the (1991) Immigration Act, applicants for permanent resident status were required to undergo a medical examination to determine if they were said to endanger the public or public safety, or cause excessive demand on health and social services. Though the clause itself remained, the specific reference to disability was removed through the efforts of advocacy groups (Council of Canadians with Disabilities, n.d.).

In the year 2000, the Department of Citizenship and Immigration exempted Convention refugees and their dependents from the excessive demand clause. They stated "it is inconsistent for Canada to accept that a Convention refugee overseas is in need of protection but treat them as inadmissible because they would cause excessive demands on health services." The Department at the time also stated "the financial impact on the provinces and territories from these excessive demand exemptions is expected to be relatively small." The government enacted the Accessibility for Ontarians with Disabilities Act in 2005. This act lays the framework for the development of province-wide mandatory standards on accessibility in all areas. Today, Ontario has accessibility standards in the areas of customer service, employment, information and communications, transportation and design of public spaces.

Regardless of the impact of the Excessive Demand clause, the points system independently impacts access for immigrants to Canada (El-Lahib & Wehbi, 2012). With the heavy emphasis accorded to educational attainment and employment or to employability, and with the exclusion that many people with disabilities experience in these domains in most countries (El-Lahib & Wehbi, 2012), people with disabilities are unlikely to have the necessary qualifications to meet the selection criteria for Canadian immigration.

Factors impacting access to health care services for immigrants in Canada. Studies examining the experiences of individuals with disablities in Canada have, to a large degree, ignored the experiences of individuals with ethno-racial backgrounds. According to The Welcoming and Inclusive Communities: Accessibility Project (2011) one reason for the absence of diversity in the literature on disability in Canada is the Immigration and Refugee Protection Act's "excessive demand". The restrictions placed on immigration when an individual has an illness or a disability, have led to the incorrect assumption that newcomers with disabilities do not exist in Canada, and as a result, there has been a lack of representation of this population in research and policy documents (Welcoming and Inclusive Communities Accessibility Project, 2011). According to the project this assumption is false, as newcomers with disabilities are arriving to Canada via other mechanisms such as Family Sponsorship and the Refugee system.

A number of researchers have concluded that settlement workers and social services may not be adequately prepared for or aware of the needs and issues facing people with disabilities. This recent acknowledgement that there is in fact a significant number of newcomers with disabilities residing in Canada has resulted in an increase in qualitative research and tools for practice addressing the needs of immigrants with disabilities in Canada (Accessibility for Ontarians with Disabilities Act, 2005; Cheikh, 2011; Ethno-Racial People with Disabilities Coalition of Ontario, 2003). A small but growing body of literature suggests that immigrant mothers of children with disabilities face significant barriers in accessing disability-related services, selecting appropriate interventions, and navigating services in culturally and linguistically diverse settings (Bernhard, Freire, Pacini-Ketchabaw, & Villanueva, 1998; Dyson, 2001; Eunjung, 2002; Kauffman, Perry, & Prentiss, 2001; Rodriguez, 2009). When immigrant families do choose to access supports and services, they are faced with many barriers to access that include fragmented services and limited resources in their native language (Rodriguez, 2009).

In order to best support the needs of a changing Canadian demographic of mothers, and to inform our understanding of development, research examining the experiences of immigrant mothers who have a child with a disability is increasingly relevant to researchers, policy-makers and service providers. As illustrated through the inherent complexities of immigrant experiences, a one-size-fits-all approach to this research would inadequately reflect the reality of diverse experiences of migration. The literature review highlights the ways in which an individual's experiences can be influenced by individual factors, such as age, gender and disability, as well as contextual factors, including policies of the host country, country of origin, family role and existing systems of support. Using a qualitative methodology to explore the experiences of Iranian immigrant mothers who have a child with a disability can provide a greater depth of perspective (Guba & Lincoln, 1994) and account for the complexities of experience. In order to account for the systemetic and individual factors that influence experience, Bronfenbrenner's Person Process Context Time (PPCT) model (Bronfenbrenner & Morris, 2006) will be used as the theoretical framework guiding the study design and analysis, and narrative inquiry will be used as the qualitative methodology for data collection and analysis.

Developmental Theoretical Framework

The following section will address Bronfenbrenner's Person Process Context Time theory (Bronfenbrenner & Morris, 2006), and its importance in framing the design of this study. The PPCT theory emphasizes, an individual's development within five environmental systems (microsystem, mesosystem, exosystem, macrosystem and chronosystem). Illustrated in Figure 1 is the immigrant Iranian woman at the moment that she was a participant in the study, in the context of Canada post migration. Within the first layer of influence, her microsystem, are individuals within her immediate surroundings. Depending on her level of support and her personal circumstances, this can include her spouse, friends, and extended family living in Canada. As illustrated in the literature review, the presence of friends and family can be a strong source of emotional support for women post-migration and aid in the process of adjustment (Dilmaghani, 1999).

The second layer, known as the mesosystem accounted for the relationship between the various components of the microsystem; within this context, the relationship between any number of people such as the women's children, her spouse and her children, her spouse and her extended family, would fall within this system. Once again, the complexity of these experiences are illustrated, based on the way person characteristics, such as disposition of the child and parents, might impact this process.

The exosystem refers to social settings that impact the mothers indirectly, such as impact of her child's school, her partner's work and disability-specific organizations on her development over time in Canada. This system also encompasses the ways in which components of the exosystem influence each other. A review of the literature illustrated that there are currently active efforts to increase types of support available to newcomers with disabilities in Canada, such as the Welcoming & Inclusive Communities Accessibility Project, 2011, Ontario Council of Agencies Serving Immigrants (OCASI), and the Ethno-Racial People with Disabilities Coalition of Ontario (ERDCO).

Finally, the macrosystem described the cultural context in which individuals developed, which included socioeconomic status and ethnicity. In this context, their own perceptions of disability, as well as the Iranian, Iranian-Canadian and Canadian ideologies and views on disability may impact the degree to which the women feel successful in their adjustment and experiences of support. The political climate in Canada and in Iran and immigration policies as well as the perceived role of women in the family will all indirectly impact the experiences of the developing woman at the centre of the systems.

Figure 1. Systems Impacting Iranian Immigrant Women

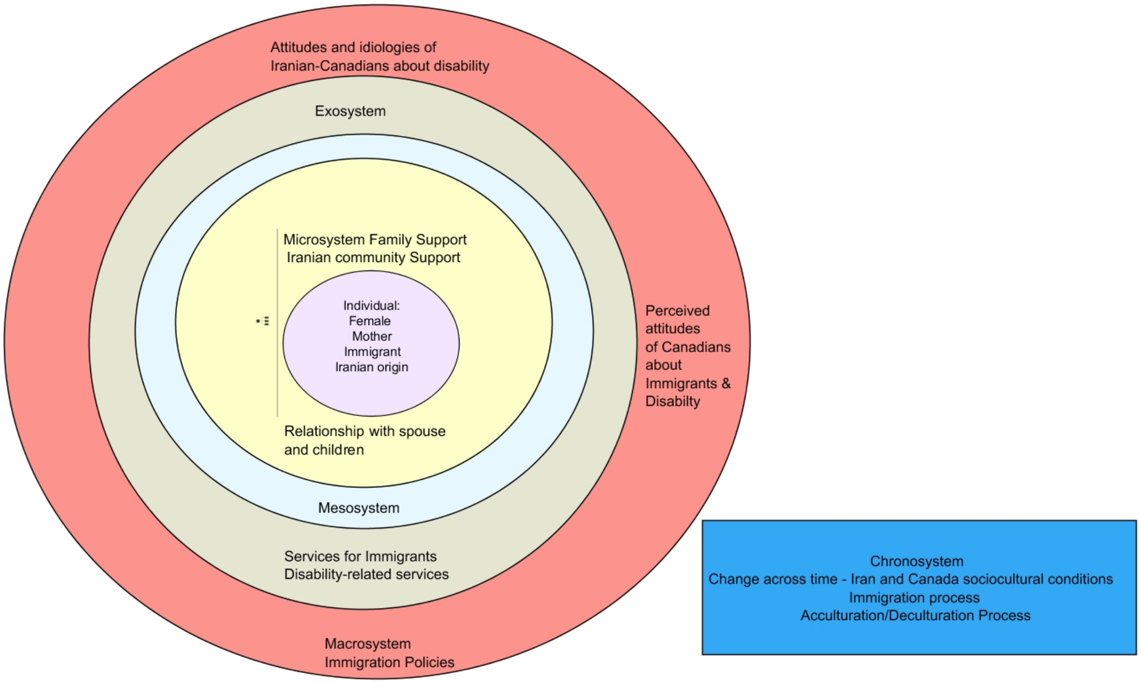

Figure 1. Visual illustration of systems impacting Iranian immigrant women who have a child with a disability based on Bronfenbrenner's Ecological Systems Theory of human development (1979).

Bronfenbrenner put emphasis on the environmental influences in development (context), however they also acknowledged that human experiences would differ significantly depending on processes and each individual placed at the centre of the systems. According to this model, there are several characteristics of the developing person that might impact their development: dispositions, resources, and demand. Disposition impact a person's processes and either increase or reduce the types of experiences they will have with different aspects of their context. By using a social constructivist lens, and narrative inquiry as a methodology, the participants should be empowered to express the way they perceive their experiences impacting their lives.

Resources include both assets and disruptive elements that might impact proximal processes. Demand characteristics are described as those that invite or discourage reactions from the social environment that can foster or disrupt the operation of proximal processes, such as age, gender, and race. In this dissertation the race and gender of participants is uniform, but the age of the participants and their children vary with a 30-year gap in both instances. The age differences in both the participants and their children, as well as the differences in diagnoses of disability and mental illness in the children may have led to distinct experiences; by using a narrative inquiry approach, these differences are apparent and each woman's unique perspective is illustrated.

Finally, time in Bronfenbrenner's PPCT theory illustrated the importance of accounting for the multiple forms of temporality (Bronfenbrenner & Morris, 2006). To be more specific, in his theory microtime refers to continuity or discontinuity within ongoing episodes of proximal processes; mesotime refers to the frequency of these episodes across days and weeks, and macrotime refers to the changing expectations and events in the larger society (within and across generations) (Bronfenbrenner, 1986).

The women in this study have undergone significant changes in their cultural context. Bronfenbrenner's PPCT theory accounts for the multiple systems of policy and organizations described in the literature review, and given it's focus on individual dispositions, demands and resources, lends itself to a narrative methodology that rooted in diverse experiences (Bronfenbrenner & Morris, 2006).

CHAPTER THREE: METHODOLOGY

Overview

This chapter presents the methodology for the current study, divided in three sections. The chapter begins with an explanation of the primary researcher's stance, describing how personal, professional, and academic training and experiences have shaped her choice of a dissertation topic and research stance. The second section presents the epistemological and ontological framework for this dissertation and a more detailed overview of narrative analysis. The last section presents the methods for participant recruitment, outlines the procedures for data collection and analysis, and describes the strategies that were used to ensure the rigour and trustworthiness of the study.

In keeping with a narrative paradigm the methodology will be in the form of a story and will be narrated in a personal voice (Clandinin & Connelly, 2000). The aim of the section will be to show how decisions regarding my approach are guided by my commitment to an ethical methodology. Ignoring social differences between the interviewer and the participant neglects the fact that the respective social roles will inevitably shape the interview process (DiCicco-Bloom & Crabtree, 2006); for this reason, reflexivity on the part of the researcher is essential. As an insider within the Iranian female community, I was aware that it was imperative to create a methodology that did not stigmatize the participants or reinforce stereotypes that might harm the community.

Before beginning any review of the literature, I first became interested in better understanding the experiences of immigrant Iranians with disabilities in a class taught by my supervisor Dr. Tara Flanagan. I spoke with her about my interest in the topic, and initially conducted a superficial literature review to understand what experiences had been recorded. I found that few studies had examined the experiences of immigrants with disabilities in Canada. I was thus prompted to conduct a literature review on the context and policies addressing the experiences of immigrants with disaiblities to better understand the limitations in literature. The review helped me to reflect on certain aspects of the research design and to construct the broad research question that guided my work: What are the experiences of immigrant mothers accessing disability-related supports and services for their child(ren) since emigrating from Iran to Toronto, Ontario?

My methodological design developed and changed over time with repeated exposure to the stories and experiences of the participants. I have made choices, mainly to protect participants from harm, but also to stay true to their stories that have modified the study's form and structure. Some choices were easier than others to make; for example, removing a Photovoice project from the study to protect participants was logistically easier than changing my method of participant recruitment and consequently changing the city in which the project was taking place. I was constantly improvising to change the structure and form of the study, and as further described in the methodology section below, every choice I made was implemented to either protect participants from harm, or to maintain the integrity of the study.

Researcher's Lens

Qualitative researchers acknowledge that the questions and construction of the research is influenced by the researchers' personal values, experiences, and assumptions (Creswell, 2007). Narrative inquiry researchers are required to justify the inquiry in the context of their own life experiences, tensions and personal inquiry puzzles. According to Clandinin (2013) this is done for three reasons: it situates the researcher in the process of being and becoming part of the inquiry, it clarifies what stories the researcher is telling and living in the research relationship, and it awakens the researcher to the ways she will attend to the experiences of research participants. In the following section, I will share my personal inquiry puzzle.

My identity as Iranian-Canadian. My story begins here, as a novice researcher struggling to understand what it means to use narratives as a means of conducting qualitative research with the Iranian community in Toronto. The process of familiarizing myself with the community in question was straightforward because I am an Iranian who grew up in Toronto. My parents immigrated in 1984, when I was 1 year old, and they quickly connected with other Iranian-Torontonians (who were at the time fewer than they are today) and I grew up immersed in the community. I attended Iranian school on Saturdays, where my mom was the teacher and my family-friends were my classmates. When I "graduated" from the elementary school, I went back and volunteered, helping students in the Farsi classrooms, and organizing group dances for the students to perform on Iranian New Year (*Nowruz*) celebrations. Looking back, I realize my immersion in the community was strongly impacted by my parents' desire to give me a sense of community in Canada that was connected to my Iranian identity. Between the ages of 8 and 10, my family moved back to Iran. During this time, I became familiar with the culture and language in a way that I wouldn't have otherwise experienced. I also immediately felt a shift in my identity as the "Iranian in Canada" to the "Canadian in Iran." This change didn't bother me; I felt different but appreciated. We returned to

Canada two years later and reintegrated into the same group of family friends. Once again, I was faced with a shift in the way others viewed me, and in a way I viewed myself.

My experience as a service-provider. When I reflect back on my original impressions and experiences with disability, I am troubled. As a young child in Iran, I was quite comfortable and accustomed to using the discourse of the *divooneh* or "mad" to refer to individuals with cognitive disabilities or mental illness. I have vivid childhood memories that individuals with disabilities lived in our neighbourhood, and that they terrified me. One particular incident comes to mind; I was a young girl, approximately eight years old, living in Isfahan, Iran. It was a warm summer day, and I was playing a game of tag outside my uncle's house with a few of my female cousins. Suddenly, my uncle's neighbour, an old man who had a teenaged son with a developmental disability came out to water and sweep the ground in front of his house. One of my cousins squealed in excited terror: "hey hey! *Bacheha* (kids!) It's the *divooneh*'s dad!! Run before he comes to attack us!" I remember running with a feeling of sheer terror. I couldn't let the *divooneh*'s dad catch me – what would his son do to me? I ran in the land across from my uncle's house for half an hour, looking from the corner of my eye to be sure the old man wasn't chasing me. I could see him limping in the distance, waving his broom in the air. When he was far enough from my sight, I slowed down, and found an alternate route back home. I remember retelling the story numerous times as a child, the *horror* of being chased by someone associated with a *divooneh*. Looking back, I see how that even as a child I was feeding the oppression of individuals with disabilities by retelling this story from the standpoint of "victim."

My views did not change significantly after we moved to Canada, and in fact, it was not until I completed a series of independent assignments in my undergraduate class in French linguistics at the University of Toronto when I read about immediate and delayed echolalia in children with Autism Spectrum Disorders that I became interested in knowing more about disability. I then began working with individuals with disabilities, and although my perspective changed, I believe that I was still participating in the oppression of individuals with disabilities, but from an institutional standpoint. Another story comes to mind that might better illustrate my point:

During my Master's degree, I held a job as a weekend adult respite worker at an organization that provided support for individuals with developmental disabilities. One Saturday, we had scheduled a trip to a nearby bowling alley and I had a young woman, Sandra, who was approximately 25 years old for whom I was "responsible." We were walking down a busy intersection towards the bowling alley in Toronto, when Sandra began screaming and engaging in self-injurious behaviour, banging her head, and biting her hands. It was one o'clock in the afternoon, on a warm summer day, and there were dozens of people enjoying their meals on a nearby patio. I knew why Sandra was reacting this way. The strong smell from the restaurant patio was making my own stomach grumble, and it was well past our usual lunchtime. As I reached over to help hand Sandra a sandwich from her backpack, our team leader came over to see what the commotion was about. I explained that Sandra was hungry and I was about to give her a sandwich. My shift leader then insisted that until Sandra successfully used her visual communication system to illustrate her hunger, she would not receive her food. I recall watching as our shift leader dangled Sandra's bag of food in front of her and walked backwards, prompting her to follow her toward the bowling alley. I was told that this would help her to reduce her self-injurious behaviours and to communicate more effectively. I was embarrassed and infuriated that I was part of a process that felt dehumanizing and oppressive. We, as service providers, had taken control of a basic necessity, food, and used it as a way of exerting our dominance on this woman and forcing her to react in a way that we deemed socially acceptable. This experience, along with numerous others as a volunteer and professional left me questioning how the environment created for individuals with disabilities impacts their behaviours and drives society's views of disability. I was prompted to begin a PhD to further my own understanding of society's impact and reaction to disability.

Experience impacting choice of methodology. As an Autism consultant, I had been suggesting strategies to teachers in working with their students without ever seeing or speaking with the children or families. This one size fits all approach had always seemed broad and ineffective, and I became interested in knowing more about the ways factors such as gender, immigration and race might impact someone's experiences with disability. A literature search on the subject revealed that at that time (2010) there was very little Canadian research on the intersection of immigration and disability. I contacted an organization in Montreal, l'Association Multi-Ethnique Pour L'Intégration des Personnes Handicapées (AMEIPH), an organization established in 1980, whose mandate is to "provide persons with disabilities from ethnocultural backgrounds and their families a resource that supports them at all stages of their integration and guides them towards the resources they need." I spent approximately 4 months volunteering with this organization, attending focus groups and on occasion, joining participants on outings.

The directors of the organization welcomed the opportunity to collaborate for my dissertation and other research opportunities. We agreed that I would recruit participants through the organization if we could conduct quantitative analyses and help the organization collect data to find out about how to best cater their services to the needs of participants. After four months of volunteering, I realized some of the risks associated with recruitment of participants from the organization. These risks are highlighted by DiCicco-Bloom & Crabtree (2006) who stress the importance of protecting information and reducing the risk of exploitation. By recruiting participants through an organization, I could not be certain that I would be reducing the risk of unanticipated harm. The women could be identified by others who attend the organization or by service providers. I was worried that recruiting through the organization may also reduce the participants' level of trust and cause challenges in building rapport. The process of building rapport involves establishing a safe and comfortable environment for sharing personal experiences (DiCicco-Bloom & Crabtree, 2006), a process that becomes impossible when the researcher hasn't done everything possible to protect the identity of the participant. I therefore decided to seek a different way of recruiting participants, and acknowledged the time I spent volunteering at the organization as an opportunity to speak with families and further reflect on questions that might frame this study.

As an alternate method of recruitment, I posted flyers advertising participation in the study in both Farsi and English around areas in Montreal, Québec that had a high concentration of Iranian-Canadians. I received a number of phone calls in response to the advertisement but none were from potential participants. After three months of failed recruitment attempts, I took my project to Toronto, Ontario; a city that also has the largest concentration of Iranian Canadians.

Understanding my own narrative is critical to narrative inquiry as it helps create transparency in how I approached the methodology.

Narrative Inquiry

Researchers acknowledge the value of narrative inquiry as a powerful epistemological tool for understanding how individuals make sense of their own experiences (Bruner, 1990). By using this approach, we can give a voice to individuals across cultures, and we consequently have the opportunity to better understand the human experience. Qualitative data can be useful in determining an emic, or insider perspective and to a certain degree, can provide a greater depth of perspective (Guba & Lincoln, 1994).

Very few studies have been done on the experiences of immigrant Iranian women who had a child with a disability, and none have been conducted in Canada. Thus, a qualitative methodology was chosen to allow for an exploratory approach to the topic. By using a narrative approach for data collection and analysis, I relied on the first-hand accounts of participants, and together, we co-created the narrative, which is in line with this methodology (Guba & Lincoln, 1994).

A narrative inquiry is an open-ended, in-depth interview in which participants share their unique stories concerning the topic of study (Clandinin & Connelly, 2000). Generally, the goal of such an analysis is to study respondents' feelings, thoughts, and perceptions of their experiences (Weiss, 1995). Narrative analysis is especially useful for conceptualizing and generating research questions about an under-researched issue in which participants are seen as self-aware and striving to achieve meaning, control, and fulfillment in life (Gergen & Gergen, 2010). Ultimately, narrative analysis allows researchers to generate new understandings of the complexities of their participant’s lives and to give voice to their experiences (Butler-Kisber, 2010). It was important to me to explore participants’ complete stories – not just what they said, but also the context in which they spoke. The decision to use narrative inquiry was based on the motivation for this study, to explore the stories of Iranian immigrant women in relation to having a child with a disability.

Qualitative Paradigm: Constructivism

Social constructivism grew out of positivist claims that the purpose of research is to discover an objective truth. Social constructivists believe that the construction of reality is influenced by relationships, and there is no objective means of privileging one construction over another (Gergen, 2001). The choices of methodology in this dissertation, as well as the theoretical framework guiding the study, support this paradigm. Narrative inquiry honours participant voices, and uses them to guide the co-construction of reality between participant and researcher. Inherent in this methodology, is the belief that individual stories are valuable and contribute to our understanding of reality. The theoretical framework used in this study, Bronfenbrenner’s PPCT Theory (Bronfenbrenner & Morris, 2006) challenges the logical positivist view that an objective reality is out there to be discovered. Through this theory, Bronfenbrenner acknowledged that experiences of development, and an understanding of the world are influenced by the way various individual characteristics interact with the environment and with time to impact the experiences of development.

Ontology. In a constructivist paradigm, realities are understood in the form of multiple mental constructions, are socially and experientially based, and depend on the individual persons or groups doing the constructing (Guba & Lincoln, 1994). A fundamental assumption of the constructivist paradigm leads to the rejection of an objective reality and suggests a stance of responsible participation. Constructivists believe that reality is invented, constructed largely out of meanings and values of the observer (Allen, 1994).

Epistemology. In qualitative research that follows a constructivist paradigm, the investigator and participant are interactively linked, so findings are co-created throughout the investigation (Guba & Lincoln, 1994). Constructivists also bring values to the forefront. Thus, it becomes the responsibility of the researcher to be transparent about their values and perspectives and to acknowledge their role in the co-construction of the participants' reality.

Procedure

In the following sections, I present the process of my data collection, its organization, and the analytic approaches that I selected.

Participant recruitment. According to Patton (1990), qualitative inquiry typically focuses on relatively small samples that are selected purposefully. Purposeful sampling involves selecting cases that provide a great deal of information about the issues of central importance to the research question. I sought to recruit eight to ten participants, first by advertising, in English and Farsi in areas of Toronto, ON with a high Iranian population and by contacting personal contacts within the Iranian community. I hoped that the number of participants would increase through snowball sampling. Accessing these participants, even in Toronto where I was familiar and integrated in the Iranian community, proved to be extremely difficult. My first participant was recruited through word-of-mouth, however, she was isolated and had almost no contacts in the Iranian community. With the exception of two participants, all were relatively isolated and did not know of other potential participants. My contacts in the Iranian community invited me to attend support groups and speak to families about disability support systems in Toronto. I was grateful to meet and speak with the various women that I encountered during these support groups and information sessions. A few additional women were recruited through these support groups, where I spoke briefly about my study and provided my contact information. Of my seven participants, the subsequent four were recruited through this method; the final two were again recruited through friends and family who were familiar with my study. Due to the sensitive nature of the topic, recruitment was challenging. In these instances, local community members can be consulted about the process as long as ethical considerations are maintained (Mack, Woodsong, MacQueen, Guest & Namey, 2005). Through this process, I came to experience the camaraderie that existed between members of our community and I was interested in knowing whether this would become evident in the interviews. All but one of the women who I contacted consented to meeting in person and to participating in the study. During my initial phone call to each participant, I explained the nature of my study, and indicated that I would like to interview them at a time and place that was convenient for them. In some cases, the original phone call lasted approximately one hour with many mothers eagerly engaged in a general conversation about disability and the Iranian community. These telephone conversations took place prior to consent approval, so although the specifics were noted for my own information, no further details are included in this dissertation.

I proceeded to arrange an appointment to meet and interview each of the women. The group of seven participants was interviewed over a five-month period. The selected participants consisted of the mother of two children with speech and language disorders, the mother of a child with a cognitive disability who was deceased, the mother of a child with Attention-Deficit-Hyperactivity Disorder and anxiety, the mother of a child with Down syndrome (whose data were not included), two mothers of children with schizophrenia, and the mother of a child with an Autism Spectrum Disorder. During this time, I was also contacted by a woman who was interested in participating in my study, but when I appeared at her home (her selected location for the interview) she disclosed that her child did not have a disability, but she wanted to talk to me about the challenges she had faced as a mother, post immigration, with the integration process. I spoke with this woman, but I made it clear that her data would not be included in this study. Another woman, who was not interested in participating in the study, also contacted me to request that we meet and speak about potential services for her son who was diagnosed with an Autism Spectrum Disorder. Again, I met with this woman over the course of two days, but her data are not included in the study.

To begin the process of data collection, I obtained written consent from each participant though a letter outlining my proposed project and a formal consent form. The original consent form and letter included consent for the photovoice project that was later removed from the study. They each signed two copies of the formal consent form: one to be retained and one to be returned to me. For the convenience of my participants, I interviewed each of them in the location of their choice. The participants chose to meet at their own home, at their work, or at a coffee shop of their choice. One participant chose to be interviewed on a park bench outside of her home. All interviews took place during the day, with the exception of one, that was in the evening. I took a snack to each interview for us to share, but found that on almost all occasions, the participants had prepared snacks and refreshments. I also collected demographic information, but I will limit what I share to protect the identity of the participants.

Participant profiles. As noted earlier, one of the challenges in researching the intersection of immigration and disability is the challenge of finding participants who are willing to participate in the study despite the stigma and risk associated with the process. By using this narrative inquiry as a methodology, women were asked to reflect back on their experiences from the point of immigration and think of how immigration and disability may have intersected to impact their experiences. Table 1 illustrates the profiles of the study participants. Ages of participants and of their children have been written as a range to protect the confidentiality of participants.

Table 1

Demographics of Study Participants and their Children with Disabilities.

Name	Simin	Banoo	Dana	Fataneh	Parvin	Ziba	Ladan
Participant age range	30-40	50-60	50-60	30-40	40-50	30-40	40-50
# of children	3	2	2	1	2	1	1
# of children with diagnosis	2	2	1	1	1	1	1
Age rage of child(ren)	3-6	30-35	30-35	5-10	10-15	5-10	Passed away <25
Birthplace of child(ren)	Canada	Iran	Iran	Canada	Canada	Canada	Iran
Child(ren)'s diagnosis	ADHD & Speech Disorder	Schizophrenia	Schizophrenia	Autism Spectrum Disorder	Anxiety disorder & ADHD	Rare disability	Multiple disabilities
Country of diagnosis	Canada	Canada	Canada	Canada	Canada	Canada	Iran
Marital status	Married	Separated	Separated	Married	Married	Single	Married

Note. Age ranges are provided in lieu of ages, and disability not specified to protect participant confidentiality.

Interview process. All participants were provided with my contact information and were asked to contact me via telephone or email if they were interested in participating in the study. All, with the exception of one, contacted me by phone. I had an initial conversation with each participant; I introduced myself, discussed the purpose and process of the study, and clarified that they could remove themselves from the study at any point in the process. These initial phone introductions lasted anywhere from five to 30 minutes, depending on the level of engagement of the participant. In some cases, participants were interested in knowing more about myself and the initial phone call consequently lasted longer than expected.

I asked each woman to choose the date, time and location of the interview. In two cases, I adapted my original plan of conducting individual face-to-face interviews in order to adapt to participant needs. Zahra, one of the two women who had asked for alternate arrangements, asked for a phone interview, to which I obliged. When we first spoke I was under the impression that she had contacted me to appease a friend. I explained several times that she was not obligated to participate in the study, and without the signed consent form, I would not use her data. She spent approximately one hour on the phone with me, during which I used the tape recorder to audiotape her on speaker. She provided verbal consent to being audio recorded, and said she would sign the consent form and return it to me at a later date. After the interview, I was unable to communicate with Zahra, and she did not make any effort to receive or sign the consent form. I took her lack of communication and her inaction in returning the form as a message that she had withdrawn from the study.

A second participant requested that we meet in a group with one to three of her friends whose children had a similar diagnosis. She explained that there was an added level of security in meeting within a group where they already felt comfortable. I agreed with this arrangement but clarified that all participants must consent to sharing their narratives with others in the group. In the end, two of the women met with me, and each spoke individually in the presence of the other. They explained that one of their friends had decided not to join for fear that she would be identified and would bring shame upon her family. I stressed to the two participants that I would do my best to protect their identities by removing all identifying information and that they were free to discontinue their participation at any point in the study. Further details of our conversations are highlighted as Banoo and Dana's narratives below.

Of the seven women who agreed to meet in person and whose narratives are included in this study, two chose to meet in their homes, one in a park bench outside her home, two in crowded food courts/coffee shops and one at her workplace. In all cases I used a ZOOM H4n Handy recorder to audio record the conversation. This high-quality recorder omitted most outside sounds and allowed me to focus on the conversation instead of note taking. The majority of participants found that the initial interview was emotionally draining; this was especially evident in the interviews with Dana and Ladan who wept at several points throughout the interview. I noted that other participants displayed changes in the tone of their conversations, revealing how emotionally charged and frustrating their experiences had become. On many occasions I offered to stop audiotaping when I perceived a participant's distress. Most conversations were free flowing, but I used probes when necessary.

Surprisingly, not many participants acknowledged my prior role as a service provider. Their language in communicating with me was familiar, occasionally making comparisons with their children, asking about my own parents, or speaking to me (in their own words) as an older sister. At times, the participants looked for my encouragement, asking me if I wanted them to continue or if they had bored me with aspects of their story. Other times they asked personal questions about my own experience as an Iranian woman living in Toronto. When they asked me questions about myself, I answered openly and honestly; I was asking them to share parts of their lives with me and I believe reciprocating this openness was a crucial component of developing trust. I was also cognizant of the difference between our disclosure: for the participants, sharing meant that they were potentially making aspects of their lives public, whereas my contributions remained between us. Due to the nature of the study, participants shared challenges they faced in receiving support for their child who had a disability. At the end of each interview process, I provided participants with resources that I was aware to access support services in Toronto. I then followed up with participants and provided additional resources when applicable.

I adjusted my study design in accordance with my commitment to confidentiality. For example, in the original study design, I had intended on following the individual interviews with a group Photovoice project. The purpose of the Photovoice component was to give the mothers an avenue to discuss their experiences in a focus group. To guarantee that everyone was able to participate in the Photovoice project, each participant was told that they would receive a digital camera valued at $70 for participating in the study. My original intention in using Photovoice as a research tool was to facilitate the process by which participants would reflect on our community's strengths and concerns while promoting critical dialogue about important community issues.

However, when the narrative interviews were completed, I felt a Photovoice project might prove more harmful than helpful. Some participants expressed an eager desire to know of other participants' stories and marvelled at how much worse it could have been for them, often creating a hierarchy of doom. It is quite evident, and frequently noted by narrative inquiry researchers, that ethical considerations must be negotiated in all phases of inquiry and that researchers are responsible for ensuring that participants are protected from harm (Clandinin & Connelly, 2000; Clandinin & Huber, 2010). I therefore concluded that I could not ensure that women wouldn't be placed in situations of harm in a focus group setting, and decided to remove that aspect of the project. Despite the removal of the Photovoice component, participants were given a digital camera valued at $70 for participation as advertised in the flyers distributed for the study.

After every interview the recorded audio clip was uploaded on my computer with the date of the interview, and the pseudonym that I had assigned to each participant. I also jotted down any salient information about the interview that would not be communicated through the audio. To ensure confidentiality, I immediately changed the demographic information shared by participants in my reflective memos (Miles & Huberman, 1994). After every interview, I spent hours transcribing the narratives in Farsi. Again, I changed identifying information for the transcriptions and used participant pseudonyms. When all interviews had been completed and transcribed, I spent months listening to the transcriptions, translating them to English and creating synopses using the participants' own words, for each story (Fischer, 1984). To create these synopses, I listened again to these tapes and transcribed key phrases and sentences that I felt effectively highlighted major aspects of their stories that addressed my research questions. I also integrated specific details and events, my field notes, and my reflective memos into these transcribed excerpts.

Transcriptions. I kept all audio recordings on a USB key that was secured in a location where I alone had access. I personally converted all audio recordings to text, using an Iranian keyboard. My lack of familiarity with the keyboard made this an extremely long and challenging process. However, during this transcription process, I developed a deep familiarity with the text. It was during this time that I began the initial analysis as I had the most significant early reflections on the text, and had the opportunity to consider the main components of each woman's narratives. By the time I restoried the woman's narratives and completed open coding for categorization (both described in depth below), I was extremely familiar with each narrative. In total, seven interviews were transcribed, with each transcription ranging from seven to ten single-spaced pages. The transcriptions used a limited number of conventions, as the purpose of the dissertation was to understand the meaning behind the words rather than the orthography. None-the-less, in this type of inquiry, where spoken language is an important source of data and variation exists in transcription conventions (Bucholtz, 2007), it is important to make use of systematic transcriptions to ensure research validity (Silverman, 2006).

Table 2

Transcription Conventions Used in the Text

Symbol/Example	Use in text
.	End of a sentence
,	Speaking pause
?	Question
…	Long pause
: “hello”	Someone else’s speech
(crying)	Action occurring during interview
time	Added stress
(**nakhodagah**)	Farsi without direct English translation

After transcribing each text, I listened to the audiorecordings and compared them to the texts to verify their accuracy. I then translated each text and asked an objective party to backtranslate sections used for the restoried accounts to ensure accuracy of translation.

Credibility or Trustworthiness

From the point of view of qualitative inquiry, the notion of defining and describing a truth to demonstrate validity has very little meaning (Butler-Kisber, 2010). It has become preferable in more recent narrative inquiries to move away from the term “validity” that carries with it the positivist understanding that there is but one objective truth (Eisner, 1991). Instead, various models are available that address how to build trust in qualitative research. Most researchers seem to prefer to evaluate inquiry using trustworthiness and credibility (Butler-Kisber, 2010). A trustworthy study includes a coherent and transparent research process and illustrates an adherence to researcher reflexivity or to a clear statement on how the researcher is situated in her work and how she accounts for assumptions or biases (Reissman, 1993).

Credibility, similar to the concept of internal validity in quantitative research, is the element that determines whether the research results are credible or believable from the perspective of the participants (Butler-Kisber, 2010). Achievement of credibility occurs by checking for the representativeness of the data as a whole; examples of strategies used to establish credibility include reflexivity, member checking, and peer debriefing/ examination. Member checking involves returning to the persons from whom data were generated to ensure that the interpretations of the researcher accurately represent the participants' experiences (Lewis-Beck, Bryman & Futin Liao, 2004). For this study, I met with mothers or spoke with them over the phone, and, when they agreed, I checked my representations of their stories with them to ensure credibility. Only one participant requested not to discuss the details of her story for a second time. Other methods used are debriefing and peer examination, where other specialists in the field may assess the field notes to establish agreement between our interpretations. I did not use this method because the defining and determining expertise would have been extremely complex. This is highlighted by Cutcliffe (1997); what would define these individuals as 'experts' or 'experienced colleagues'? What specific criteria determine whether someone else is an expert in someone else's story? Further to the issue of the expert, the production of categories/themes depends upon the creative processes between the researcher and the data (Munhall & Boyd 1993; Schutz, 1994) and it is unlikely that two people will interpret the data in the same way and form the same categories and themes. I concluded that to establish credibility, there was no better expert than the participants, and in the end, we collaborated in constructing our representation of the text. To strengthen the credibility of the study, I established regular meetings with some participants throughout the study process and used the participants' own (translated) words in the restoried narratives.

Catalytic Validity

In this dissertation, I have moved away from positivist forms of validity that support the notion of defining and describing a particular truth. However, I will address catalytic validity, which is determined on two levels to reflect an open and directly testable commitment to enhance equality. At the first level, the intention is to break down the researcher-researched distinctions that typically privilege the researcher (Habermas, 1990). At the second level, catalytic validity is determined by the degree to which participants find themselves energized and reoriented by their participation (Merrick, 1999; Stiles, 1993). In this narrative inquiry, both levels of catalytic validity were particularly significant and I was cognizant of their importance at every step of their research process.

At the first level, the researcher-researched distinctions certainly impacted the nature of the participants' responses. I was very aware of my own stance as a researcher, a service-provider, and as an insider to the Iranian community. I used bracketing, a process by which I made conscious efforts to identify and set aside my assumptions (Johnson & Christensen, 2000) prior to conducting the interviews. As a female Iranian researcher and service provider, it was natural that I had my own assumptions and beliefs about the experiences of Iranian immigrant women. I actively reflected on my own perspective before, during, and after each interview, and I engaged in reflexive memoing to explore the possible impacts of my own perspective.

Dr. Nathan Smith, a member of my dissertation proposal committee, originally brought the second level of catalytic validity to my attention. He questioned my motivation behind every decision in the study-planning phase, and stressed the critical importance of conducting research that benefitted and empowered participants. Through this conversation, I became more attentive to every aspect of the research design and I attempted to ensure that every aspect of the methodology addressed, when possible, the necessary processes of change within the community.

All of the seven women whose stories are shared in this dissertation expressed that they felt personally empowered to support other women living through similar experiences because of their participation in this study. Two women, Banoo and Simin refused compensation for their participation, and communicated adamantly that the ability to help others through their narrative and create positive change in their community would be their compensation for participation in the study. This level of social justification is a critical component of narrative inquiry where researchers must consider the theoretical and policy changes that might occur as a result of the inquiry (Clandinin, 2013). Future directions to facilitate this change are discussed in chapter six, the conclusion of the dissertation.

Three-Dimensional Space in Narrative Inquiry

Engaging in narrative inquiry involves thinking in three commonplaces: temporality, sociality and place. Being aware of all three commonplaces simultaneously is what distinguishes narrative inquiry from other methodology (Clandinin, 2013). Attending to the methodology and analysis in a temporal way, points researchers toward the past, present and future of the people, places, things and events under study. Sociality refers to the personal and social conditions at every step of the research process. Personal conditions refer to "…feelings, hopes, desires, aesthetic reactions and moral dispositions…" (Connelly & Clandinin, 2006, p. 480) of the researcher and participants, while social conditions refer to conditions in which the experiences and events are unfolding (Clandinin, 2013). The third and final dimension of place refers to the "…specific concrete, physical, and topological boundaries of place or sequences of places where the inquiry and events take place…" (Connelly & Clandinin, 2006, p. 480). Throughout the data collection and analysis phases of the study, I was living in this three-dimensional inquiry space, cognizant of the ways temporality, people and places impacted us as we co-created narratives. For example when meeting with each of the participants, I was aware of the ways our interactions, the location and the temporal nature our conversation impacted the way the narrative unfolded.

CHAPTER FOUR: THE NARRATIVE ANALYSIS

In this chapter of the dissertation, the results are presented using two complementary approaches. The first section presents restoried accounts of the seven women's narratives that provide the context for each of the stories. I checked the validity of the restoried accounts with participants to ensure they adequately reflected their perspectives. Keeping in line with the narrative paradigm, these accounts are written in narrative form and highlight the components of the three-dimensional inquiry space: temporality, sociality and place (Clandinin, 2013).

Part One, Simin's Story:

I meet Simin outside of her apartment complex during the time that her three children are in school. She has a warm, welcoming smile, and invites me to join her on a bench in a park in front of her home. Our meeting place appears to be a great concern for Simin, who apologetically explains numerous times that, had her living arrangements been different, she would have loved to invite me to her home for some tea. A few days earlier I had spoken to a member of the Iranian community who worked in an organization providing activities and support to mothers and their children close to Simin's house. Simin had taken my number from the service-provider, and we had had a number of lengthy (20-30 minute) phone exchanges prior to our meeting. She was eager to share her story with the hope that it would help other women in her situation. I have not included details of the phone exchanges, as they were not part of the informed consent. All our exchanges, over the phone and in person, were in Farsi.

On the day of our meeting, we sit on a bench in the middle of a park between her apartment complex and the organization through which we met. I ask if she is comfortable speaking in public, especially so close to an organization where she receives support, knowing that others may hear our conversation. She laughs and says “let them hear; I haven’t killed anyone, I haven’t done anything wrong and have nothing to be ashamed of. Let them hear.” She smiles and waves at acquaintances who walk by. She then asks me to begin the interview. And so I encourage her to begin speaking with my first prompt: “What have been your experiences as an Iranian mother with a child who has a disability (in Iran, during the immigration process, and in Canada)?” The interview is being audio-recorded and I hold a pen and paper to record any nonverbal messages that are communicated. I am able to concentrate fully on listening to Simin knowing that I can transcribe the interviews and re-listen for analysis at home. She is full of energy and speaks with enthusiasm as the words spill out of her. I am fascinated to sit and listen as her narrative gains momentum and her story takes shape in the following way...

> I have one daughter, and two sons. My two sons have been diagnosed with speech disorders, and all three of my children were born in Canada. I can tell you based on my cousin’s experience what it’s like to have a child with a disability in Iran. Would you like me to?

I indicate that I would prefer to hear her first-hand accounts. She continues…

> After I had my sons, I was worried because they weren’t speaking as early as my daughter had, so I asked a Public Health Nurse to tell me if my kids really had a problem and if my worry was warranted. The nurses were the ones who told me what particular speech and language services to use. So I contacted the number they had given me, which was a number for speech and language services across the whole city and they did an assessment with me over the phone. Well after

> that, I started putting my child in speech classes. I used these classes for two sessions… they were really small group classes. The speech pathologist would work with the students and she would give us a sheet of paper to come home and work with the child.

Long pause

> I really didn't have anyone to show me where to get help. Well, when I was pregnant I used services that were for pregnant women, but I only found out about these services when I was pregnant with my last child.
>
> Actually, I would go to the classes during my first two pregnancies too but because my English wasn't really good, I didn't understand what the woman was saying at all. I think it would be good if in our own community we had some separate programs to tell mothers how to best teach their children. I tried to find my own support and bring my mother to Canada but they didn't give me a visa… Maybe, if my mother was here, I would be able to do a lot of things. I use a day care now; I'm able to use it with a subsidy. But if my mom were here, I would never leave my child in a day care. I would leave my child with my mother and I would divide up my workload. And I would have a source of happiness. I would be healthy. I'm not healthy now, in my own opinion. I would be mentally healthy and I would be able to give of my own positive energy to my children. I have gotten to a place where I've made myself a bit sick. What I mean to say is that I'm depressed and finding this energy is a really difficult thing for me. But, if I was a mother who was not depressed, well I'm 100% sure I would be more successful. When my children see my nervous, depressed expression, the feelings

> are automatically transferred to them. I truly believe that children see and understand everything…
>
> When I came to Canada, I was a 24-year-old girl. A 24-year-old girl who had been raised in a home filled with love. After a while, God gave me my children. At that time, I had no experience. I had no knowledge. For example, here we have a community centre with programs that mothers can use. But at that time, I didn't know that. You can teach your child to swim, draw… it's free! And people who receive government support can receive a 'welcome policy' and they can have certain advantages. I think that if a newcomer mother were to arrive now, I would try to provide her with this information. I really believe that if I had received all this information at the time of my arrival, I would be ahead of where I am now.

I ask what she means by saying she'd be ahead of where she is. She clarifies:

> At this point, I am a 35-year-old woman. By 35, a woman should have already done everything that she wants to do. She should have studied, she should have a successful marriage, and she should have all her children. If she wants to have a job, she should have chosen her job by now too. But I'm 35, my language skills haven't improved much considering I've been living here for 8 years and I'm somebody who has no job. I'm 35 and I still haven't found my life. This is all because I've fallen behind…
>
> I grew up in a family where, if I hadn't fallen in love, not only would these troubles not come up, but I can say that I would be set for a perfect life. Now in any field I could have been a professional. I could have been an ideal mother.

Sometimes you notice that you're talking to someone who boasts that they're ideal. They say: "I make food for my children, I clean the house"…but no! This is not an ideal! To be ideal you have to put your children on the right path from their early childhood. One of my problems is that my husband will say, no, we don't have money, this is the way it is. Well, I really don't believe this. Not having money **is** a problem, but I can take my child's hand and teach him how to draw. And well I worry, because I think, if my child's speech doesn't improve, he may become shy and withdrawn and maybe he won't be able to advance in his studies, as he gets older.

One of my problems is that I'm living with my husband… and I can't get him to leave me alone. I've even called the police, and he's returned twice crying. A lot of people say: "when he comes, don't open the door on him or call the police again." But in that moment when he's crying, well my child is crying too. Well when I see my child crying, I cry. I get frustrated and I'm depressed… okay so I call the police, the police come and how does this all look to my child? How does it all feel for me and for my nerves? I wanted some kind of service where they could secretly take me to a new home. Or another service where a man could help my husband so my husband could then fix himself. But they don't help.

The frustrating thing is if I cry, or if I hurt myself, or take pills to kill myself, then they'll come help me. Or if I say: "yes yes, he hit me! He hit me and my kids!" instead of being proactive so that dangerous situations don't come up, they're waiting for it to happen so then they can say: "this person is dangerous." One of the things is that they always tell us: "no, you have to decide yourself that you want to do something." Well I'm saying I'm now in circumstances, I don't have anyone here. You know? I have no service. You just give me some money so that I stay alive. Well what about my soul? How am I supposed to pull myself up? People need a source of happiness. Now think I'm alone and have nobody here. And because of my problem with my husband I can't develop any friendships. All of a sudden we're completely ostracized from society. Because of the problem that he has, we have to keep ourselves far from people, because if someone finds out, they pull themselves away from us. Look, I don't want to be ostracized. But my friend has a healthy husband, and they live together. One day she might come to my house, look around and find out my husband is a drug addict. She won't come back to my house again. She'll cut off all contact with me because she'll think about it and worry that maybe her own husband will be influenced by mine. She'll also wonder: what can I learn from this person? And really, what does he have? So I try to keep my problem for myself. Tomorrow my child will reach an age where she wants to get married, or find a boyfriend, or just a regular friend. This will be so hard for her! These are all my problems! With all these problems, how am I supposed to sit and do speech therapy with my child? Everyone tells me I'm a good mother, but I say, no I'm not good because I **can't**, not that I don't want to, but I don't have **time** for my children. I don't have time! And you have to realize that I'm a human being too! I'm not a robot. I'm human. At some point, I get tired too; I need someone to comfort me and to massage me. But I have never had that person here. And the only thing I think about is that I was responsible for these three children.

> Unfortunately here, one of the problems in our Iranian community is when I try to talk about my problems, they act so superior to me that I get stuck in what I'm saying. Everyone puts on a mask, sits down, and tells you nonsense as if they know everything. If I didn't know better, I would have believed a lot of the things people told me. I speak of my experiences so openly because I don't want anyone else to make the mistakes I made! If we can have a warm community and all help each other… we'll all suddenly see that we were all able to pull ourselves up and out of bad situations. Look I haven't committed a crime! I've made a mistake! I chose a bad case as my husband. But he's a human being too… sometimes I let my emotions get the better of my sense. Maybe if everyone was like this the world would be a more beautiful place. I will push as hard as I can to see if I can make him into a good father for my children. This will be much better than if my children are raised without a father.
>
> Just think, if we really had a strong community with good communication, and good service-delivery, well this can be a very good thing for our Iranians here.

Part Two, Banoo's Story:

After spending a month in Toronto unsuccessfully trying to recruit participants, I decided to attend a number of support groups for Iranian newcomers. At the end of one of these sessions, a tall and soft-spoken woman in her sixties approached me and asked for my number. She said that she would pass my message on to her friend, who may call me to speak about her experiences with her daughter who has a disability.

I received a phone call the following day and I recognized the caller's voice from the support group. It was the woman who had approached me for my contact information. She introduced herself as Banoo. It was Banoo who would be willing to speak to me about her own experiences with her daughter and son who both had disabilities. She explained that she, along with four other families, had formed a support group for Iranians who had children with disabilities, and they now meet every few months to advocate for their children as a group, and to brainstorm the best ways to navigate the system. She asked if she could meet me at the same time as two of her friends from the support group as they would feel more comfortable sharing their stories in their support network. I was happy to oblige. Our phone conversation was short, lasting only five minutes, but in the process, we set the date and time of our meeting: Thursday at one o'clock in the afternoon, in the food court of a busy, crowded mall.

I drive to the mall and rush to the food court, hoping to arrive early. When I arrive, I instantly spot Banoo, sitting with one friend and three cups of coffee. As I sit down, Banoo offers me a warm smile, and a cup of coffee. She introduces her friend as Dana, another mother of a child with a disability who is willing to participate in the study. I sense hesitation and anxiety from Dana, so I immediately take some time to introduce the study and to review the consent forms.

After some pleasantries about the weather, the coffee, and our commutes, Banoo begins her story.

> My two children were diagnosed with schizophrenia. Does that count as a disability? Can we talk to you about schizophrenia?

It takes me only a moment to consider this. These women's stories and experiences are valuable, and if they are willing to share, I will be grateful to learn about how mental illness has impacted their experiences. I indicate that I would like to hear her story. I had explained the purpose to Banoo at length over the phone, so she requires no prompts or questions before she continues…

> Both my children have schizophrenia. My daughter is 37 and some of her behaviours began at 16. She complained that she didn't like Iran and wanted to leave for a foreign country **(kharej)**. She would say support was better in kharej and she would be happier outside Iran. So we applied for Canadian immigration and hoped that by coming here, her behaviour would improve. My daughter's behaviour, and the home environment where we were constantly at war, fighting with each other, had a negative impact on my son, who was 10 at the time. The boy, who was really studious, really gentle, really wise… well, there was a lot of pressure on this boy. He would tell us: "Please! Just take her to the hospital!" We would tell him "But there is no hospital that will accept her! Nowhere will take her! We can't even take her out of the house!" Anyway… that's how we ended up coming to Canada. When we first came to Canada, well, we were all in the same house, and at first the girl wasn't too bad. You know, the environment was new. But then after a short while, she started with her yelling and fighting, so we took her to the doctor who said: "she's sick! You have to take her to the hospital even if just to catch your breath." So we went and we admitted her to the hospital where they diagnosed her with schizophrenia and paranoia. After that the social workers put her on disability support benefits because she was 21. Now this was another challenge. We had so many fights getting her to sign this paper – she had a negative outlook on everything. She finally trusted a couple of people who she had developed a friendship with when they told her nothing bad would come of

her signing the paper requesting disability support benefits. So she finally signed and thankfully everything with benefits was sorted.

Once the paper was signed my daughter said: "I don't want to live with these people, I want to go to a group home!" She didn't trust us. She didn't want to live with us. In the hospital they had told her great things about group homes, and they had given us the address to three downtown. And so we went, the three of us, me, my daughter, and my husband… the three of us took her suitcases and went to a group home. We were immediately shocked! Group homes are terrible places! Especially for us…. with our culture. So we told my daughter that the home wasn't an appropriate place for her. And so she started to scream: "no no! I want to stay!! What's it to you! You should just leave!!"

So, what could we do? We left. It was about one to two hours after we left that she started calling us: "it's bad here! Come pick me up." So the next morning we went back, picked her up, and brought her home. In the end we found a hospital that was really good – they had a unit specifically for young people. There they taught her how to live independently. My daughter loved it there. She was there for a few months, but then they said it was enough and she had to go to a group home again. So then they took her themselves and showed her a few places and from the ones they showed her, she liked one. It wasn't a very good place. One day, at four o'clock in the morning, our daughter called and said she was in a hotel. She said the group home was bad, so she went to a park, called a taxi from there and asked that they bring her to a hotel. So the taxi driver brought her here, to this hotel… where she had locked the door and was sitting behind it, terrified of any noise she would hear. She was convinced someone was going to kill her. So she asked us to go over and save her. So, at five in the morning we headed to the hotel, picked her up brought her home. This same kind of incident repeated for 16 years until finally one day her doctor recommended a group in the hospital where she had her folder. Her doctor said they would help patients keep track of their medication, help them find accommodations… and basically give them any support they needed. We were so fortunate to receive this support. My daughter joined this group and they reached the conclusion there that she really just can't live with anyone. Through them she was able to find an apartment to live and she now lives on her own but visits the program at the hospital twice a week. They see her, give her medication and her injection. If she doesn't go one week, they come to her house and ask why she didn't go. Here, I don't have any family or friends… nothing. So I call the group and tell the nurse: "I call my daughter's house, but she's not there." The nurse says: "okay don't worry, we'll go to her house now… or we'll call the police and see if they can help us." They follow up right away.

As for ourselves, we never really received support. We were the ones who always had to provide the support. Unfortunately this sickness is so taboo that you can't even talk to your friends about your problems. Actually most people first assume that there must be something wrong with us – we must have done something to our daughter for her to turn out this way. Because you know, my daughter was normal until she was about 16 or 17 years old. We were really good to her. Whenever friends and family would see her, they would see a really good, successful and together young girl. So in the end they assumed that we must have done something wrong for her to end up like this. Nobody really knows much about this sickness to come and empathize with us. Everyone wants to give us advice, or they want to complain to us. When she was first starting to act out in Iran, I took her to the doctor who scolded me for wanting to medicate such a young woman. At that time we ignored some things – we assumed she was acting out because of puberty. Everyone would tell us not to argue with her, give her whatever she wants… I mean, even I sometimes think maybe we were too hard on her. Maybe if we weren't hard on her, things wouldn't have turned out this way. Or I think the boy wouldn't have turned out this way if my daughter hadn't had these problems. With him, sometimes I think if he had grown up under better circumstances, he wouldn't have turned out this way. So yeah, that's how it is. We think that we lived in Iran during a time of war, and as parents we really didn't have normal emotional states. I mean, everyone had a certain level of anxiety; there was war, we were thinking of whether we could leave the country… we had to run around, get things done. In reality, there was no peace or calm in our home for a while… and this was the time when our children were really small. I don't know what to tell you… I would drop my kids off at school, and half an hour later the bombings would begin. I would run over to their school to pick them up and take them to a shelter. It's possible that all this had an impact on my children. And we… well in that time we were under so much stress… that well… we didn't understand anything.

> At this point, my daughter is living independently in an apartment, she has a boyfriend, she's given birth to her own son… yeah… she's become a mother… but they've taken the child away from her. The Children's Aid Society's taken her child away. They won't show him to her. So now, the nature of her problems have really changed. For example, she's always insisting that I buy her an apartment. She wants to own her own place. So this is our problem now… in each stage, we get to a new place. A new problem. Yeah.
>
> My son, he's reached the point where we have to convince him that he's sick. That in itself is really challenging… to convince him that he's sick and to convince him to take medication. Because my son never stayed in a hospital… I mean… I'd had so much trouble with my daughter I wasn't willing to go through the same steps with my son. And in general, because of my daughter's rough character, I wanted to keep her away from me. But my son is a sweet, innocent, and attached boy. And he's continued to stay attached to me. In a way, my daughter's negative attitude worked to her advantage… to a certain degree, she's independent. Now my problem is that my son will say: "yeah, I got sick. My environment was bad. It's your fault that I'm sick. You made me sick. My sister made me sick." My problem is that I now have no support to adequately integrate my son into society. To make him, to a certain degree, independent. To distance him from myself. For example if we want to go anywhere, even just to the park, I have to go with him, walk with him, and come back. I have to go everywhere; do everything with him. But he was a really smart boy. Even still, we'll be discussing something intellectual, or we'll be stuck on a problem, and he'll

> suddenly have the answer. He knows a lot about physics and math… and history… he's probably already read about 100 history books. His general knowledge is really high. But the thing is, he keeps asking what he can do with his life. I tell him he can write a book. He has so much knowledge! I tell him to sit down and write or translate a book. But he's so negative. He thinks there would be no point to writing. Nobody would read his books. Then he starts asking why we brought him into this world. He says this life isn't worth living and if we hadn't brought him into the world, it would have been better. He says he's useless. So yeah, what I really need now, is for a way to integrate my son into society. I need to find support for him.

Part Three, Dana's Story:

I look over at Dana, who has been sitting patiently to the side, listening to Banoo's story. I immediately notice tears have started to form in her eyes. I ask if she wants to take some time before beginning her story. She doesn't. She requires no prompts or leading questions. She begins with a shaky, almost frantic voice.

> My child didn't have a diagnosis. She was a good girl… and well, she was also really quiet. She also had exceptional talent in drawing and visual arts in general. But then she started to say she didn't want to go to school. We really couldn't believe it. You know, this war that Banoo was talking about, it's something that only we can understand… and unfortunately it's something that here, when we try to talk about it in the hospital, they show no emotional reaction. No matter how many times we say, in Tehran we were continually faced with bombings! Every child needs to have some calm around them- this child didn't have that. They

> keep asking how she would sleep at night. Well, we keep explaining that when your child is three years old, with the loud sounds of airplanes flying overhead, she wakes and stays awake until morning! She was our first child, so we didn't have any experience to know if the way she was reacting was normal. When we say this in the hospitals they look at us as if we're trying to avoid their questions. For example, they attacked our neighbour's house, and their child was friends with my daughter.

Dana pauses and tears stream down her face. She apologizes several times in a shaky voice. I ask that she take her time, and remember that she is not obligated to speak to me if she is uncomfortable. She continues…

> They attacked my neighbour's house, and they were never able to recover a single one of their bodies. And these people here, when you try to explain the circumstances to them, they just don't understand! I've had so much trouble over just this. And then they speak to me in a way… they completely accuse me of changing my words and being inconsistent. But now from what I see in the field of psychology, I really don't know if those cries and the sleepless nights were the result of the airplanes during the war, or if they were the result of all our movement because of the revolution or because of… well how do I know!?! In that time, in Iran, schizophrenia didn't exist! Or at the very least there were very few cases! Now years later, when my child was at home, if there was thunder and lightening, I knew I had to put soft music on. To give her a sense of calm, to let her know that she's safe. But now, for example, she's in the hospital and when there's thunder and lightening, I call and I tell them that my child will be afraid.

Then the nurse says: “don’t worry don’t worry don’t worry”… the next day I go over and see that yes, because of her anxiety, she’s wet her bed. And so they tell me: “no, this is the impact of psychosis, we have to medicate her.” They basically completely ignore… this is a cultural barrier and language barrier.

Banoo’s daughter has a special quality… and I really admire her mother for it, I’m sure she’s learned many things from her mother: her daughter explains things. She speaks. But my daughter, for example, doesn’t speak at all. She can’t express her needs. Just think, in these circumstances I have to be her voice!

When we came to Canada, my daughter was about 17-18 years old. We came in the year 2000. Then after a while a friend of ours who was living here suggested we call a crisis line. We already had one friend living here. So we called the crisis line, and they took her to the hospital. There, the first thing they did was put the label of schizo on her… unfortunately. I wish they hadn’t. I wish she had received a proper assessment right from the beginning. Because at the time, I wasn’t really fluent in English, and I wasn’t familiar with the system. And now when I look back, I realize how quickly they put some labels and diagnoses on her that I find unbelievable. You know I wasn’t able to read at all. I just didn’t understand the way the system worked. I hadn’t studied psychology in school.

I remember my child would say she wanted to go home. So she came home and less than one week later they took her back to the hospital. She kept insisting she wanted to come home, but her dad would say no, you have to stay here in the hospital. She was forced to stay and was unhappy for a month. She couldn’t even communicate… she didn’t know the language. And we had thought, well, at least our challenges with language and culture, etc. are solved by now. We thought we were in an advanced first world country. We didn't know what it was really like! I mean, just immigration itself was a huge stress on my daughter and it really made things worse. The adjustment… even still, my daughter hasn't been able to properly adjust to the new environment, and she hadn't developed the language skills… she hasn't been able to accept… it's hard.

Yeah, after that she went to another hospital and they diagnosed her as bi-polar and said she had a personality disorder too, and they just gave her a series of varied diagnoses. They have given my child 15 diagnoses until now. For example, we'd have a family meeting, and the doctor would say: "no, this isn't schizophrenia, it's bi-polar." But when the doctor wanted to document the meeting, to protect him/herself, he/she writes it's possible that my daughter is bi-polar. But he/she also writes the previous diagnosis, but changes the medication to that for someone who's bi-polar. If the medication yields successful results, then great. If not, then they can go back and say it was schizophrenia like they had originally thought. In this same way, they have given my child 15 different diagnoses up until now. After that they said they'd place her in a group home. One mistake we made at the time… maybe if we had allowed her to go to a group home, she would have better adjusted to society. But in any case, there were no Farsi-language group homes, or ones that would ever have services in Farsi or just be familiar with our culture. I changed my field and studied behavioural science/behavioural therapy and I started working with children who have an Autism Spectrum Disorder, and through my work I learned how to manage situations with my child at home. I worked in a group home, and did art therapy and used picture exchange communication systems and so I learned everything at work.

Then unfortunately something happened; my daughter had to have her teeth pulled. She had a tooth infection but we had to sit on the waiting list for nine months. Because of her over-sensitivities, she needed to be under general anesthetics. But my daughter can't say if something is bothering her. She can't express herself. And so yeah, nine months was really hard. We went to have it pulled at a private clinic, and they said it would cost us $1500 for each tooth that they pulled. I said I would pay it, and Ontario Disability Support Plan didn't cover any of it. But I said okay, put the money together, and waited for an appointment. It was the summertime and it took the private clinic three months before they gave us an appointment. Sometimes my daughter wouldn't even want to come to the dentist with me – I had a hard time taking her there. Other times it was on their end that they would cancel. Anyway, this infected and turned into a urinary infection. She had pain in her side and couldn't even tell me that she had an infection. But when she walked, I would see her hand on her back. I took her to the hospital and they operated on her. It was after that operation that she became more restless and she seemed to become upset more often. One day she pushed her caregiver. They took her to the hospital and immediately put her in the mental health unit. She really wasn't fit for that unit. She couldn't speak - she couldn't do anything. The first thing they did in the hospital was they threw her… they locked her up. They threw her in a room. She didn't have water. She

> didn't have a washroom. She had nothing. She was there for three and a half months. And there, she couldn't even ask that they turn the light on for her. **Twenty** minutes was all my child was allowed to come out of the room, and even then three security guards would accompany her.

Pause. Dana is crying more openly now – obviously distressed at the memory. I remind her to continue only if she is comfortable sharing her story. She composes herself and continues as her bottom lip trembles.

> I have all the letters. I would beg them and say: "please let my child feel calm for the half hour that she's allowed out of the room." But when the security guard would come, they would yell at her and sit and laugh amongst themselves. I had made notes of everything… I've written it all down. So I took it when we had our meeting for the crisis intervention plan and asked that they explain the conditions in the hospital. They told me they couldn't do anything about it. They told me to send a letter to the director of their unit. So I did as they asked and nothing happened. There was no point. They called the police and interrogated my daughter, and she got her first criminal charge in the hospital. She was locked up for one and a half years, my child.

Dana stops for another short pause. Her lips are trembling and the tears continue to flow down her face. Banoo has her arm supportively on the back of Dana's chair, and we both wait to see if she is able to continue. I feel terrible resurfacing painful memories, and I want Dana to stop if she is uncomfortable speaking. She insists that she wants to tell her story. If she can help even one person avoid her situation it will be worth it. She continues speaking with a quivering lip and a face full of tears.

They didn't allow me to see my own child for three weeks. For 22 days, my child was locked up there, restrained, and I didn't have the right to see her… because they had simply written that it was a safety issue. I had a meeting with them last week – I still have the letter from the meeting. In her care plan, they've written "impulsive aggressive, hits her mom". So I say: "it's been three years that my daughter's been visiting with me under your observation. If you have even **one** case of when my daughter was aggressive with me, you have the right to bring it and talk to me about it. But when it hasn't happened, why would you write it here?"

Whenever I speak with other families, I realize my child isn't alone in this. There was just another child and they did to her as they'd done to my daughter. They threw her in solitary confinement in a hospital for three years and put a criminal charge on her.

For three years, I went to every civic centre around here to see what the regulation would be if I wanted to set up a group home. Our problem was, see… within the Italian community for example, they have a secular church that gathers people and funds and goes to the embassy to get support for people within their community in need. But us, who are we supposed to go to? The Iranian embassy? You want us to go to people and ask for support? Until today all of us have learned to hide our children's disabilities and mental illness… in our community, we see this as a source of shame. Well see, many of the problems that we have now... the system doesn't formally recognize our culture, our language and us. What I'm trying to say is, this lack of support is in our community, in the Afghani, and Tajik

> communities as well. Our community is so weak in this respect. In this hospital here, the stats that they provided indicated that 9% of the people in the hospital are Iranian. 9% is not a small percentage! But I went and said that my child wanted to watch an Iranian film because she doesn't understand English… they looked at me, surprised, as if to ask if my daughter is in a hotel. You know?

Dana appears to be exhausted; she looks over at Banoo who smiles at her reassuringly. We continue speaking for some time, discussing her frustrating conversations with service providers and their lack of accountability for the diagnoses given to her daughter. She then shares stories of others in their support group who felt uncomfortable sharing their stories from fear that they might be exposed through identifying information and bring shame to their families. I acknowledge their concerns and explain that every effort will be made to remove identifying information and protect the participants from harm. I also remind them that they are not bound to the study, and that they can remove their stories and their participation at any point in time. Banoo leaves us as she has to meet her son, but I spend some time walking around the mall with Dana, talking about her efforts in advocating for her child and other Iranians with mental illness.

Part Four, Fataneh's Story:

I am rushed in meeting with Fataneh. I have taken a part-time job as a research assistant at Sick Kids Hospital, and I try to find time to interview mothers when I'm not working. Thankfully, up to this point, we have all managed to align our schedules. It's now 11:40 am and I rush to meet Fataneh at 12 pm – I have another interview at 3 pm and don't want to rush either participant in their story telling. I show up to a busy Tim

Hortons near Fataneh's home, and spot a woman sitting alone at a table. I hesitantly approach her and smile. She immediately stands with an outstretched hand and introduces herself as Fataneh. She asks if I would like something to eat or drink before we begin. I get myself a coffee with resistance from Fataneh who offers to pay, and we both sit down. She begins her story:

> My son was born in Canada in 2001. Overall, he was a very happy and lively boy. From the time he was three, I put him in an English day-care and they always complained that he didn't listen to others.
>
> My field is accounting, and I was working in Iran. When I came to Canada I took courses and upgraded and finally found a really good job in the head office of a major corporation. I was always exhausted when I left work… and well, you expect that at the very least when you come pick up your child they'll say something good about them. They would always say: "he didn't listen, he did this, he did that…" but at the same time they would say: "He's so funny, dancing and singing… but he's not listening." Then he went to junior kindergarten, and he could read all the books. So I spoke to his teacher… because children who are really good at English and who know their alphabet and numbers can go to French immersion. It was then that his teacher said something to me that I think I didn't fully understand at the time. She said: "he doesn't have any problems in an academics, but socially, he does." But I didn't understand at the time what she meant by this. I took him to French immersion and signed him up. French immersion schools have no support; they don't have educational assistants like other public schools do. From day one this child had problems and we had no

support. They kept giving us reports that he has problems. Then one day his teacher told me: “have you done a psychological assessment for him?” It was then that I made an appointment with his family doctor and at first he said my son might have ADHD – he gave us a questionnaire, and one to his teacher. Then he compared these questionnaires together and said no, your child has a sickness by the name of Asperger’s. I had never heard of this… so I was crying and crying… I kept thinking how is this possible? We had at least heard of ADHD, it was a bit more normal for us. So I went to an organization for children with Autism where they were giving group seminars and I took a few classes. I had heard a lot about Autism but I didn’t think Asperger’s was the same as Autism at all. But they told me: “no no no, Autism is like at one end, and this is at the other end… it’s high functioning. Children with Asperger’s have a lot of good qualities compared to children with Autism but they have some negative qualities too. Long story short, it was a horrifying feeling.

In terms of support, the most important support that I had was my husband. My husband did a lot of research on his own. He would tell me that it wasn’t important, at the end of the day, my son is our child and we love him. Since we didn’t want to pull my child out of school in the middle of the year, he stayed with no support. Anyway, the next year we kept him in the same school again because they had promised to provide a teacher with expertise in Autism. We had all the same problems… the teacher really didn’t have that grasp of these children like they had promised. And so the complaints continued. My head would spin a thousand times a day.

The next year we put him in an English school and told them about some of the challenges he has and got him and educational assistant. Things weren't great there either, because you know, educational assistants aren't professional people… they just come and sit down next to the child. There was a man, an old man, who acted exactly like his slave! It was as if he had someone stuck to him all the time; my son would get angry and yell: "why is he always stuck to me?" This had turned him into an odd child in the classroom… because everyone in the class sat in round tables, and this child had a man sitting next to him who was looking at him all the time. I would come home and see that the man had done his homework for him – he would say the words, and the old man would write them. And other children don't play with these types of children because they see that someone's always stuck to them.

In the third year that my child was in this school, they said: "it's really hard for him in this school, it's hard for us too, and we're sure it's hard for you too. There's another school that's not in this area but we'll provide a car to pick him up to bring him there, where they have a community room." They said there was a class there where my son could be well integrated. So we went to visit one day. I went on my own and I saw that all the children seemed to be delayed. For example, it was a grade four class, but they were working on grade one material. But they all looked normal, and their teacher was very nice. Then I told the teacher right there that my child doesn't have any of these same problems – it's true that he has social problems, which they had too, but doesn't have academic problems. If he comes to this school, he'll be bored. The teacher said they work with each person at their own level. I thought it wasn't a good option for him, but they said it would be a very good class for him.

I took my son one day and asked him if he liked the school and he said yes. They gave us a tour, they showed him the library, and they said in the classes at the school everyone could use a laptop. At that comment, he fell in love with the school, mostly because he loves technology. So he started at that school, but again it was the same complaints. We were under a lot of stress. So my husband and I decided that I would quit my job, and just stick my energy to our child. At the end of the day, he is our life.

In the beginning it was very difficult for me, but I went and told my boss that I wanted to leave my job. It was as if our lives suddenly changed, mostly because we were able to relax a little. I took classes to learn how to best work with my child. I went to their school library and began volunteering once a week.

You know, for nearly two years I did nothing but cry. There was a meeting once, and a young boy who had Asperger's and had gone to University to study computer science was speaking. He spoke about his principals and his mother who were so supportive… and he explained that he is no different than other children while being unique in some ways. It's true that the boy was very successful, but I kept thinking oh no, will my child end up the same way? I was crying. When his talk ended, I went over to speak with one of the women who he'd introduced as his previous school principal. I wanted to ask her what school she worked at so I could take my son to the same place. But when I went to ask this question, the tears kept pouring and I couldn't speak.

I decided to consult a psychiatrist myself, because I thought I couldn’t sit like this and cry every day. That day I was really upset, I kept wondering why I wasn’t able to speak. I wasn’t saying much of anything; I was just trying to tell the woman that my child was the same as the speaker. But you know, when you have that feeling of sadness you automatically pass it on to your child. I used to cry often and speak a lot to my oldest sister. She would comfort me by saying all children were the same.

Now because of hormones, my son’s started asking questions like how babies are born. It’s scared us a bit because we’re unsure of how to handle these questions. And now he even comes and touches me. Last week I called his school and asked if the same things are happening at school. The teacher said they talk about boundaries at school. So, this is how it is. Our troubles are up and down. This is something that’s now really occupying our thoughts. When he goes to high school, what if something happens, and he’s not able to think properly? I would talk about this same subject with my sister and she would say oooooh, regular girls are boys have the same problems. If there’s no protection, they have children too. These thoughts can really upset you. But overall, I’ve been really lucky here. I was a person who lived a really routine life in Iran. Then I came to Canada and I started studying a bit and I found a job. In this time I also met my husband. My husband is an incredibly good man. My husband always tells me that my son is the biggest challenge I’ll face in my life… and I need to find the best way of working with this challenge.

I take some time to thank Fataneh for sharing her story with me, before I turn off the audiorecorder and we leave the coffee shop. I have another appointment in approximately an hour.

Part Five, Parvin's Story:

I received a call from a woman who had heard about the study through a friend; she said she knew of a number of people who would qualify for the study and might be interested in speaking with me. If they were comfortable contributing, they would get in touch with me. One of these women, Parvin, contacted me immediately.

I am rushing to meet Parvin after my meeting with Fataneh. I drive about 10 minutes from the Tim Hortons to Parvin's office and feel unsure of myself as I walk in; there are a number of men and women in suits behind their desks. I mention to one of the women that I have a meeting with Parvin. She asks me to take a seat and calls her to meet me. I am faced with a tall woman dressed in a gray suit, with her hair perfectly styled in a short bob and light make up. She appears to be approximately 35 years old and has broad shoulders and a hoarse voice. I am not sure of what I expected, but I am instantly taken aback by her strong presence. She summons me into a large meeting room with floor to ceiling glass windows. There is a large boardroom table and chairs in the centre of the room, with seating for approximately 20 people. I feel intimidated and uncomfortable and wonder if this is the best environment to conduct the interview. I look at Parvin who appears at ease. She looks out the door and tells the receptionist to take her messages as she'll be busy for the next hour. She then asks me to take a seat and offers me coffee, tea or water. We sit side by side at the corner of the large table. Parvin indicates that she is ready to begin…

> Okay. How would you like to start this?

I prompt her with the same broad question I had used with Simin…

> What have been your experiences (of support) as an Iranian mother with a child who has a disability in Iran, during the immigration process, and in Canada?

She responds

> In Iran, I had a lot of family support; I was a working woman, so my mother and sister would look after my child. I never needed government support, and in all honesty, my daughter didn't have significant problems. We were living in an environment surrounded by family, issues would resolve themselves.
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> After immigrating to Canada I started to make use of government services. I was using counselling services on and off for about 10-12 years. I didn't have many concerns with my daughter, but my son, who was born here, strongly believes that he's Canadian. He wants nothing to do with our culture; he keeps saying: "If you think/act a certain way, it's because you're Iranian; us Canadians, we're really peaceful." It's like the system here has gone directly in his blood. The way they interact with him at school, I won't say that he's brain washed, but it's obvious that he's being raised with this system. One of his problems is that he feels he can't make any friends; he feels really lonely. Now I've taken him to a psychiatrist a few times because he's been diagnosed with ADHD and he's very insecure. He's a child with no self-confidence and with a lot of anxiety.
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> His anxiety is the result of the conflict my husband and I have in the home. This is something that my son has said. I sense unrest in this child, which is why I'm so worried about the impact of our arguments on him. In reality I'm trying to do

something to reduce some of this tension. Which is hard because we came from Iran where we were middle class and had a place in our own community. Now we're struggling to keep ourselves at the same level here. We work longer hours outside the home, we put a lot of time with our children and when our child has a problem we blame each other. My husband blames me a lot. He says if I had put more time with our son, he wouldn't have turned out this way.

Well, I'm not one of those mothers who believe I should put all my time for my children. I have my own time, and my child has his time. That's why I've been after my own projects too and I've been involved in the community. Sometimes I think maybe the only mothers that are successful are those who sit at home and just put all their attention on their children. And well, I hear all the blame for it now. When there's blame, there's argument, and when there's argument, the child hears. I mean, this is a cycle that just keeps continuing.

You see, here, in our loneliness, our children only receive affection from us parents. There are no aunts or grandparents. I am really attached to my family, and even after 14-15 years, I'm still homesick. If they were here, I would have a whole other kind of emotional support. Now in Canada, I've found a number of services to support my children. It started from their school because I was constantly receiving letters from their teachers. I made an appointment and spoke to my family doctor who referred me to a child psychiatrist, and from there, they said we had to go to family counselling. We went to family counselling and a couple of times my husband came too. Husbands usually believe that it's not working and if you have to see a psychiatrist then you're crazy and they're crazier than you are. That's why we went for a few sessions and then we stopped going. But now since he's gone to grade six, I've gotten a few letters from his teacher and I've convinced my husband that we should go back again.

In terms of support, what can I say? What support? There are friends, but I believe that when a person comes across a difficulty, they need to seek professional help. For a while our friends would say if we ignored the problems then they'd go away on their own. In our culture these things exist… people say: "well, he's just a child!" or my husband says: "You're being too hard on him. This is normal." In reality it's like I'm protecting them in a way. I've always gone to seek help, and I'm still in the process of seeking help.

The majority of our friends also have their own issues: they either all have depression, the majority are taking medication… and I'm not willing to get help from someone who is numbing herself by taking medication. I had a doctor who supported me – he was very good… but he passed away. After that I didn't find a doctor that was as good – who would take the time and really speak to you. I really notice something lacking in this system: really, not everyone is able to pay $150-$200 an hour to a psychiatrist for help. And old-fashioned psychiatrists are much better in their practice than newer ones. The person that I used to see would spend an hour and fifteen minutes with me each time that I saw him. He was over 80 years old and had spent over 40 years practicing. He would help you get to know yourself. I'm not looking for someone to see and to speak with. But you know, not everyone can afford this. What I was using before was covered by OHIP and that was really good for me.

I’ve now decided to cut back on my work and spend Wednesdays playing basketball with my son. I also put my son in art classes because I feel it might reduce his stress. I’ve decided that I will go on the ground and work with him. My husband still blames me that I haven’t taken my son for enough other activities. Basketball class is one hour per week. Swimming is one hour. In total classes are five hours altogether. Well what am I supposed to do with all the other hours? A lot of mothers are at home and they’re able to put the time with their children and take them out. I’m always out and in reality, I’m the breadwinner of the family. For women who work outside the home, it’s really interesting that I’m still blamed as a mother, as a housewife. When in reality, I’m not a housewife! My husband had a specialty back home, but well he didn’t find a job in his field here. It’s not his fault. He can now go and get a job in another field but he refuses. But I don’t accept the image that society has of a woman. I even question motherhood itself. I believe that I’m able to replace my role with that of my husband and become the provider and I don’t blame him for this switch. My doctor said: “you’ve accepted this. But as an Eastern man, he now sees himself in a position of weakness. He’s lost his power and in this way he blames you saying you’re not an adequate housewife or mother. He says you’ve always been after your own priorities and your friends and your own activities, etc.” But in reality, my biggest challenge is now my husband.

When I was living in a small town in Ontario, we had formed a committee for women. Part of what we did was supporting women and mothers who had recently immigrated. To teach them the laws, help them further their education, study, and adapt to society. If they had a problem we wouldn't involve ourselves, but we'd send them directly to a counsellor, and we had translators who would go with them. We were active for five years… but after that we heard so many negative comments and so many things happened that we stopped the committed entirely. Now it's been a year that I've been living in Toronto and I'm involved in some organizations here… and a few of us would like to do such a thing. At the very least I see the need for such a thing here. Because honestly, the first generation immigrants are all full of problems; they have all accepted that "that's the way it is" or they're depressed or passive. Even if there are a few active people among them, those who are passive have pulled them down. But the thing is, it's the second generation (our children) that really need the help. The best place to help these children is really in schools. The children with difficulties should be identified, and they should receive help in schools. Exactly like what happened to me – although I was the kind of person who went to them and asked for help. Us Iranians, all we care about are the terms of education. As long as the child becomes a doctor or engineer…. I'm one of those people. Aside from what I did for my daughter, I told her even if tomorrow you want to go flip hamburgers or if you want to go mop floors, that's your choice… but first you have to get your PhD, in any field that you'd like. I really believe in this. I think it's the key. That's why I want schools to be more involved when there are problems; because either families ignore the problems, or they can't afford to deal with them, or they don't have the time to take their child to a counsellor or a doctor.

Part Six, Ziba's Story:

I stop and pick up a box of chocolates before going to Ziba's house. She lives in a high-rise building at the corner of a busy intersection. I take the elevator up to her home and ring the doorbell. She opens the door and welcomes me warmly. Her home is unlike anything that I have seen. Every corner of the living room is covered with dazzling furniture: two mannequins in the corner modelling elegant dresses, a large chandelier in the middle of the room, and big Persian carpets covering the length of the floor. Every corner of the living room is covered in photos of a man and a young boy who is a mirror image of Ziba. The table is covered with sweets and fruit; my humble box of chocolates is added to the spread. She brings me coffee to drink and we settle in her living room. It's a weekday so her child is at school. Before we begin, she notices me admiring her decor and she tells me that she has always been passionate about interior design and fashion. She has made the clothing on the mannequins herself and if she were financially supported, she would pursue a career in this field. She tells me that the photos are of her boy and his father. She begins her story without hesitation and I ask her to restart as I turn on my audio recorder.

> My boy developed speech and learned to walk later than other children – I knew this well. They gave me an amnio test in the hospital when they found out he had a rare disability. They gave me a series of materials… some brochures to read, some surveys to fill out and some websites to visit. This helped me get information and have an idea of what steps would come.

Ziba spends the first hour of our meeting describing her son's diagnosis in general. I have not heard a lot about this condition so I'm interested in hearing more, however, I would like to know more about her personal experiences. So I probe, noting that she appears to have found a great deal of information on her child's disability.

> You seem to have found a lot of information on this syndrome. Does it mainly come from the websites, brochures and information given to you at the hospital when he was first diagnosed?

She responds

> I find a lot of it on the Internet myself too… although I don't like to search anymore because it frustrates me. I'm always terrified that I'll find things that are worse and worse. And I'm becoming depressed… so now I try not to think about it at all. I just take things one step at a time. When the issue comes up, I deal with it; for example, I had a meeting at my son's school last week because his teacher believes he gets easily distracted in class when she tries to teach. So he just gives up and wants to get up and leave. So I reminded her of his diagnosis and she said they just wanted to bring it to my attention so I would know why he's progressed so little this year. He's in grade one now, and the ratios in his class are really excellent: 12 students, and five or six staff. Unfortunately his school only has kindergarten and grade one. Higher grades are for Autistic children. So next year he'll have to go to a public school. The school that he'll be attending next year already has his file. What happens if he goes to a public school and he can't understand what the teacher is saying? 30 children to one teacher… or even 15-16 children per teacher… he/she will have no time for my child! And then it becomes hard for my child. I keep reading these websites and blogs of adults who found

> out they had the diagnosis after they got married; they all became depressed, quit school, don’t work… they’re all unhappy with life…
>
> When I had my son, I was on welfare, because I had just graduated and I found out that my son is this way and well… I felt really sick. My doctor didn’t know anything, nobody helped me or provided guidance… no, I was completely alone. They didn’t even refer me to any organizations from the hospital. They didn’t really have any information to say for example: “well you are having difficulty, and need emotional support… you’re this, this, this… well here’s a number of someone you should contact for help.” Even my own doctor, my OBGYN who was the specialist in that hospital… I got sick when I was giving birth and even she didn’t give me any information. She didn’t say: “here’s some help, some guidance, since you’re completely alone.” Nothing. But then, if they had given me the contact of an Iranian, I wouldn’t have stepped foot to meet them. You know?

I ask why

> I don’t like it at all! Because if I went to an Iranian they would say: “the girl got pregnant! Look at her! With a bastard child! And look the child has problems and she’s kept him. Young woman, do you not have a brain? Why didn’t you get an abortion?” You know? When I started hearing these things, I pulled myself out of the Iranian community… because I didn’t want to get an abortion, but I knew what I was doing to myself. I knew what challenges were ahead of me. I knew I would have no future… and well, all this happened. I lost everything, I became financially bankrupt, I had to use my credit card to live… I had no money… I

> knew all of these things ahead of time! But when it came down to having the abortion I just wasn't able to do it. It wasn't because of religion… no, not at all. But this is how I felt in that moment. I wasn't able to do it. Come look at his picture. He's a beautiful boy. He has such a sweet face.

I take some time to look at his picture. I agree that he is a beautiful boy.

> So yeah, I pulled myself aside from Iranians. Completely. And now I feel more protected. And now the social workers that come see me, they're Canadian, and they're great. Is it really necessary to be counselled by other Iranians? I go to people from other cultures so I can easily talk about how things were. When an Iranian comes over if you try to describe the same things… and then… well now I only have one friend who comes over. I haven't told her my full story... I mean… the real history with my son's father. She thinks that I've been married to a man she's never met and now I'm going through a divorce. What am I supposed to say? Should I tell them that I got into a relationship with a married man? Well because he's a millionaire everyone will think I went after him for his money. And now they'll say what happened is good because what goes around comes around. They'll say: "She went to screw with some guy's wife, so God punished her by putting this kind of child in her lap." You know? Well, these are the kinds of things they say! I already know what they'll say! Why should I take my son to these places to have people laugh at my son? They'll say: "the child is a bastard... his mom is…" you know? Do you know what I mean? Well, I'm not proud of what I did, but I don't agree with what they say. So I have to protect my child… I don't want to take him somewhere where people will humiliate him.

> But you know, I explain all these things to my social worker and she says I have to live my life and this is all my own business.

I note that she seems to have found it helpful to have the social worker and ask how they first got in touch.

> When I first found out I was pregnant I would go to my doctor for check-ups. I think she told me there was an organization for pregnant mothers who were alone and had no one to support them and didn't know how to take care of themselves… like me. Through that organization someone would come in the house, help me find my way with motherhood - for about an hour a week. When they could no longer help me, this organization then gave me the contact information for another organization and that one to another… and so on…. Until finally my son's hospital introduced this last organization that I'm now in touch with; they even filled out the forms for me, and put me on a waiting list for 9 months. Through them we got a worker, who was such a wonderful woman… and from there they took my son out of the waiting list and registered him for senior kindergarten at his current school. This worker who was now coming was really supporting both of us. If I was upset about something, I could speak with her, and if I was upset I would call her… if I needed to go to court she would come with me, if… for example, I needed to go somewhere I could ask and they would come with me… they would accompany me so that I wouldn't get frustrated alone. They helped me in many ways. They come in our house and speak with us, and see what kind of needs we have: if we're low on food, they show us where the nearest food bank is, if we need financial support for

> disability-specific services, they connect us with the appropriate organizations. They even helped us fill out forms to receive the financial support. This woman later told me I could have received financial support from the day he as born. So she helped me contact them and they paid us from the time he was born.

The phone rings and Ziba runs to answer it. She appears to be distressed throughout the 5-minute conversation. She hangs up the phone and mumbles something about some forms she needs to complete for the person over the phone. She then apologizes to me and continues her story.

> Yeah… you know, if I had my parents here, there is no question that I would have had an abortion. I didn't have one because I was alone. There was no help, and I hadn't told anybody that I was pregnant and I really had to make the decision completely on my own. At the end of the day, if you have your dad and your mom, you're not alone when making decisions. I was really scared. I was terrified. I couldn't sleep; it had become somewhat of a phobia for me. And in that time if I had gone right away for the abortion… I wasn't even two months! It would have been much easier. But I kept killing time. I was terrified and my child's father was partly to blame. He didn't stand behind me; he abandoned me. He put me under pressure and then left. He said the baby wasn't even his. I think he did this so he'd be free from both of us. So I would think to myself: "well he left me too, so maybe I really should go have an abortion." But then when he found out I gave birth to the child, and he found out the child had a diagnosis, he was completely shocked and kept criticizing my decision to keep the child. Now he feels bad about what he had said to me, because he really loves our child. My

son is such a sweet boy. He's happy and joyful. If he were here with us now he would be climbing all over you.

But I'm still under so much pressure, and I'm suffering from depression and anxiety to the degree that I'm receiving financial support for my own mental health problems. That's what the phone call was about earlier. Before getting any financial support for my child, or myself, I was using my credit card to pay for everything. My income didn't even cover my rent and my child's father was unwilling to help. He kept telling me he would pay me when he could but he was lying. I ended up running through all my credit cards and filing for bankruptcy. After that I realized my child's father wasn't helping me, I was forced to call my own parents. For two years, they would send me money. My child's father then started giving us $800 per month, but by that point I was receiving $920 from welfare, so they would deduct that amount from our welfare amount. My rent was $1100 per month so I had to get the rest of it from credit cards. There was so much stress; my life collapsed. Do you know? Do you know what I mean? I became sick after all this. My parents were getting angry and yelling about my child's father: they wondered why he wasn't helping me if he had so much money. So I asked him why he wasn't helping me. I told him my parents were sending me their retirement money. I said they were old and shouldn't have to worry about me at this point in their lives. It was at this point that my child's father showed me what he was really like. I had believed that he would really try to help me up to this point. But he said: "So what!?! Let them pay! It's their duty and it has nothing to do with me! I'm already giving you $800 per month in child

> support. I don't believe I need to give you more than that. I don't live with you so it doesn't make sense for me to pay any of the rent." When he said all these things, I kicked him out of my life. At this point everything was done. Finished. My family helped me a lot. Thankfully my family is relatively open-minded. Eh… they weren't happy about the situation, but they always supported me. So far I've gone to Europe three times to visit them, and they shower my child with love. My mom, dad, brother, sister.. ouf… he's like the only grandchild, he's spoiled. And to everyone in Iran, to the rest of our family, well I haven't been to Iran in 15 years, so they've just told everyone I'm married. Yeah. They haven't even said that I've divorced. Why should I go back? I have no reason to go back… even though I have nobody here… if I go back everyone will talk about how I've separated.

Ziba asks me some questions about my dissertation, my partner, my family and myself. I feel comfortable in her presence and spend another 15 minutes speaking before I leave. I feel that we've developed a strong rapport, and as I leave, she invites me to go back and visit if I get the chance.

Part Seven, Ladan's Story:

My last interview is without a doubt my most memorable. My mother had gone grocery shopping earlier that week and noticed that the cashier (Neda) was an Iranian woman. Somehow (I still can't quite imagine how the conversation came about) my mother managed to talk about my research and asked if the woman knew of anyone who might have a child with a disability. 10 minutes later, my mother was home, and informed me that she had given my number to Neda who knew of someone who could potentially participate. The woman who was referred often came to the grocery store with her son, who was in a wheelchair and who appeared to have an intellectual delay. I was told that Neda would give her my number when she saw her next.

I was skeptical that Neda would pass on my message, and at first, she didn't. But, my mother came back from another trip to the grocery store with a number in hand. The woman had gone grocery shopping and, true to her word, Neda had spoken about me and asked if she would be interested in my research. The woman (Ladan) responded that her son had passed away a year ago. She wouldn't be contacting me, but if I felt that her story might be relevant to my research, I could give her a call.

I sat with the number in my hand for a while, deciding whether or to contact the woman; I didn't want to impose if she had not been comfortable enough to contact me. I decided to call her, to explain the purpose of the study in depth, and to explain clearly that she could withdraw from the study at any point in time. Every one of the stories I had heard were different in their own way, and this woman's story was a story worth hearing. She is a mother, she is Iranian, and for 23 years, she raised a son with a disability: first in Iran and then in Canada. So I called the number, introduced myself and the study, and I asked if she would be comfortable meeting in person. Ladan sounded brisk over the phone, and I can say with confidence that I have not been this nervous since the start of my study. She gave me her address and told me that I could meet her in her home at 6 pm that night, after her husband had left for work.

I drive through suburban streets at 5:45 pm trying to find the address given to me earlier today. I know these neighbourhoods well; the homes are expensive and the families are generally wealthy. I come to the house and park on the street. All the lights in the home are off, and I wonder if I have the right information. I get out of the car and ring the doorbell.

A woman answers the door. She greets me kindly but in the same brisk manner as over the phone. I enter the house and notice immediately that all of the lights are in fact turned off, with the exception of a dim light in the living room. She apologizes to me and quickly turns on a few more lights. I sense her grief and although she is kind and smiles, I feel that she does not trust me. She shows me the couch in their large living room. The dinner table is set for six and the coffee table is covered with fruits and sweets. I wonder to myself if they will be having guests later in the evening. Ladan notices me looking around and comments on the set up of the tables:

> My husband loves people; he always keeps the house ready for guests, with sweet offerings permanently on the coffee table, and the dinner table set with enough places for anyone to feel welcome to join for dinner.

The home is large, spacious, and immaculate. I move to the living room and Ladan tells me to make myself comfortable.

> I'll make some tea. Have a seat. Maybe I can help you with your research. I don't know if I can. But maybe.

I wait for her to join me on the couch and provide her with an overview of the study and the consent form. She looks them over carefully and signs the forms saying that she'll give them back to me when I'm leaving. I assure her that if she doesn't want to give them back, I will not use any of her data. I ask if she is ready to begin. She is. And so I ask my sub-questions: What were your experiences with a child with a disability in Iran, through the immigration process, and in Canada?

> What do you mean my experiences?

I elaborate that I want to know, for example, about her experiences of support.

> Our family didn't support us at all. I see some families here really have grandparents, aunts, and uncles involved in everything. We didn't have any real support in Iran. My mom had passed away when I was about 17 years old and my mother-in-law couldn't accept that our child had problems. And on top of that, she really wasn't the kind of person who would want to take care of her grandchildren. My father didn't like my child at all. He would say: "It's because I love you so much; I can see that your child upsets you, and I see your sadness, and it makes me dislike your son." There was this place - it was like a day care. I put my son there for about 3 months, from morning to the afternoon. In the afternoon I'd go pick him up. One day, the daycare's cook told me they would tie my child up to a chair during the day. I didn't take my child there and under no circumstances did I trust the woman who ran the daycare again. In any case, it was soon after that that we prepared to come to Canada. But in Iran, we had no support. Not from family, and not from the law.

I inquire if they had any difficulty with the immigration process.

> Yes. Before we came here, they announced that my son couldn't see well; he was slowly going blind. So I sent all his medical documents to a hospital in Toronto and got an invitation from the hospital to come to Canada for an operation. After we entered Canada, we requested to stay under humanitarian grounds. They accepted my husband and I with work permits because of our son. The hospital sent us an invitation saying it wanted to do an operation on my son who might

require a couple of eye surgeries. We had to make sure we had the money to pay for everything before coming. I think at that time it was around $21,000 that we had to pull together. Because we were paying for everything, we had the invitation to come. That was around 13 years ago. When we requested that our son stay on humanitarian grounds, it was about six or seven months that we had already come. At that point I had already gone and checked out some potential schools for my son. At that time, we didn’t have health cards. My husband would cover all our son’s medical expenses. The only thing is I got a job at a school, and my insurance would cover my son’s medication. So, I can say that my son received no financial assistance from the government. Then our lawyer told us once we had our health cards we should accept our status as landed immigrants. This was five or six years after we had arrived in Canada. We could have applied for immigration after three or four years with our work permits. But when we applied for immigration, the Canadian government accepted our status as landed immigrants, but not our sons. They gave all three of us health cards. Our lawyer told us to return the health cards and not accept them. She said they might deport our son. So we returned our health cards and we waited again for three years. In three years we applied again; adding that on to the five-six years from before, this takes us to eight-nine years since we’d been in Canada. And so after nine years, our lawyer applied for us again, and we filled out all the papers they were asking for. We did all this and waited for around two and a half years. I was really counting down the minutes to becoming a landed immigrant. But while we were waiting we were busy. My husband and I were both working; his

> medication was covered by my insurance, and he was covering all other expenses. When my son passed away (pause), at his funeral, our lawyer told us she didn't want to act badly or be rude, but she asked for my son's death certificate. She said if she had the death certificate we would quickly receive our immigration (tears). So we gave the death certificate.

Ladan pauses and begins to cry softly.

> So, we gave my son's death certificate about 10-15 days after he had passed away. Our lawyer…you know, she was a really good woman. She kept insisting that we bring our forms, so I finally took them in. Although, our lawyer had already spoken to immigration and said that in our family a child had passed away.

Another pause as Ladan continues to cry.

> They were only waiting for that sheet of paper. Here, they just put a stamp on the death certificate, and they don't accept any photocopies. My lawyer later told me that as soon as I had called her, she had contacted immigration. My son passed away on a Friday, my lawyer had contacted immigration by Monday, and they were only waiting for that sheet of paper… the death certificate. Three months later, they gave us our immigration, and we had been waiting for two and a half years. Our lawyer had told us not to expect anything soon because immigration would take a long time because of our son. And to be honest, it wasn't too important for us, because the three of us were living in Canada together, we were working, and we had built a life for ourselves. The only problem we really had, was if we left Canada, we wouldn't have been able to come back. But I had told

> my lawyer that it wasn't a problem. We have enough to see in Canada to keep us occupied for 20 years… we didn't need to make trips abroad. This was really unjust (**namardi**). Imagine, just two months, two and a half months after my son passed away, they announced that we should take pictures and take some documents and we then received our cards.

She pauses with a long silence. We sit in silence as Ladan stares off into space. We then sit together for approximately 10 minutes drinking our tea. She smiles at me and I sense that she now feels more comfortable sharing her story with me. She asks me if I've tried an Iranian sweet on the table. I try it, and we spend some time talking about sweets, Iranian food, and where to find the best variety in the city. I am filled with admiration for this woman throughout our interview, but I don't find a way of expressing myself. She insists that I take home the box of sweets on the table. I take this as *tarof* and politely refuse. She insists, and then goes on with her story.

> Since I worked in a school myself, I already knew of a lot of organizations where I could take my son in Canada. I took him about 5-6 times to a place that offered respite to parents. We weren't really accustomed to having him go anywhere on his own, so we would take him in at 10 am on Sundays, and pick him up at six pm. We never let him stay overnight. And since they knew we didn't have any sort of governmental support, they had agreed to charge us $20 each time we dropped off our son, from 10 am to 6 pm. We would do this once a month because they were usually really busy on Sundays – they had a lot of children at their centre. During Christmas and special occasions, forget about it. It was impossible to get a spot. So I took my son there for five months. The last time I

> took my son there, the old man that worked with him had abused my son. When I picked up my son at 5:30 that day, I saw that he had scars all over his body. I had taken pictures of all his scars, but my husband asked me to get rid of them, so I did. I wanted to give the pictures as proof, but then I realized my son already has all this information on file at the hospital. My son's hands were all bruised too. So, I took him back inside, and thank God for the woman that was working there. I showed her my son's hands and feet, and pulled up his shirt to show her his body. This woman told me to take him to the hospital immediately. "This minute" she said. So the next morning, Monday, we went to the hospital. We were there until Wednesday morning! So they examined my son at the hospital and we explained the situation to the doctors and nurses. In the meantime, the director of that respite centre had been calling non-stop. The doctor asked us to take the child home and to go back the next morning. So we went back, and were greeted by the Children's Aid Society. I was so happy; I thought they were there to help us. Because I know something like this kind of abuse is not taken lightly. At the hospital the doctors had concluded that these weren't insect or animal bites; it was a human who had done it. Since I had witnesses that my son was at the respite centre right before coming to the hospital, and since I had shown his scars to someone at the respite centre, I called our pastor to come and help us, so he sat with us and the people from the Children's Aid Society and they filled out a report and we took it to the police. But they didn't do anything with the report.

I ask who had contacted the Children's Aid Society.

The director of the respite centre. In the end, they said since my son couldn't speak for himself, and he was basically the primary witness, they couldn't prosecute the worker. They would just refrain from giving him jobs in the future. Honestly, this was all very painful for me. You know why? Because I thought judgment here was better than in Iran, and I trusted the police. After that, I didn't take my child to the respite centre anymore. Organizations that I met at my son's school did fundraising for my son, so we were able to get a home worker through respite services at home.

The first year that we were here, we felt really alone. By the second year, we always had parties in our house. I mean, my husband would invite everyone to our house for Thanksgiving. So every year, Christmas, Easter and Thanksgiving we would have all our friends who had nowhere else to go at our house. We would put up around five or six trees for Christmas and we would decorate. Honestly, my husband is a really kind and generous person. We'd invite everyone over and we'd party, dance, and eat until nighttime. We wouldn't go over anywhere at night because my son had to take his medication at night and sleep in time. So we would start the Christmas party at lunch, and my son would dance and enjoy himself throughout the day. We had a LOT of parties. But we knew all the people we invited. I didn't go to parties where there would be people we didn't know. The thing that was really hard for me to take was all their questioning. If nobody asked me any questions, I would have been okay with it. But they would start asking me questions, and they would take me back. You know? Back to the early days. And this would make me feel bad. At our parties,

> everyone knew my son. Everyone knew how he was and they wouldn't ask about his condition unless I wanted to talk about something. But I wouldn't talk much because I knew they didn't have the knowledge to help me, or the experience to know what I was going through (**ham-pa)**. They would only upset me more. They would ask a lot of questions, but they would also give their opinion. They would just tell me what they thought, you know what I mean? (Exaggerated sweet voice) "Did you eat anything that was bad for you during your pregnancy?" It was then that I wanted to tear them apart with my nails. Do you know what I mean? So we went to parties, restaurants, and we would go out and enjoy ourselves.
>
> In all these years that I've been in Canada, two things have happened that have made me pull myself away from the Iranian community. The first was one was when the head of an Iranian television station here… I don't know how well you know that man.

I share that I had met him a few times, but I don't know him well.

> Well, we were in a mall, and our pastor had a booth there. He had asked that we go by and help him pass pamphlets out to people. So we took my son there after church so he could pass out pamphlets with us. My son was making some vocalizations, like: "eeeehhhh….eeeeehhhh". So the head of the Iranian television network came and said: "take this child outside." I told my brother who worked with the producer that I was surprised by his reaction. He could see that my son had a problem, and he was sitting next to a booth representing the church. You know? I couldn't believe that he said: "take this child outside. He's

upsetting people." So our pastor and my brother both went and told him that our son was a blessing. But anyway, we left feeling sad.

There was also an incident once when we went to an Iranian bakery/ice cream shop in the city. I went with my sister-in-law and our kids to have some Iranian ice cream. When we got there, my son was excited, so he said: "eeeeeeehhhh". I told him he had to wait for them to come give us ice cream. Five minutes later, he made another vocalization: "eeehhhh"… I told him again that he had to wait. By the time he said "eeehh" for the third time, the woman who was the owner of the bakery came and said: "can you please take him out of my store? He's upsetting my customers." So I looked around; there were four men sitting there eating ice cream. One of the men said: "excuse me, when did we tell you he was bothering us?" The owner said: "no, this isn't the kind of environment where these kind of children can come." I immediately left with my son. When I hear something like that, I get really upset. My sister-in-law then left with my two nieces, but before leaving she said: "Miss, what you said was terrible, I won't ever forgive you." After we left, the four men who were sitting in the bakery got up and left with us. The owner of the bakery ran after us apologizing and asking us to return to her store. I told her: "look, I hadn't come in your store to eat food or to eat ice cream for free! I had brought my son and my nieces so they could learn about Iranian culture, food and dessert. I hadn't brought them expecting a favour from you, or thinking you wouldn't take money from me. What you said to me today, that was enough to convince me… I'm never coming back here."

> So in the time that I have lived in Canada, these two things have stood out for me in our community, and I can never forgive them. It was after that that I just put everything Iranian aside. Because… on the other hand, I tried to understand their perspective. I would think okay, well this man who's head of an Iranian television show, he's probably set up a booth hoping to make a profit. So that's the thought I had when I told my husband we should leave, after he asked us to. We have no need to stand around and argue with someone when they don't have the capacity to understand. You can't teach someone to react with intelligence and respect. He doesn't see; he doesn't understand; he's ignorant. Why should I waste my energy on him? Initially my husband got upset and wanted to respond, but I took his hand and said: " it's Sunday, we've just left church. Let's go home. I think it's best of we just leave." We've met a lot of these types of people in our community. One of them is my own father! My very own father would say: "Don't bring your son here. When I see him, it upsets me. Because I see he brings hardship to your life and that upsets you. So I don't like to see him." So I wouldn't go to my father's house. Who cares? This was my dad's capacity. So he loved me, but he was incapable of loving my child. So, yeah, after all this, we didn't go back to that bakery, and we decided to pull away from the Iranian community.
>
> So then, this was our support in Canada. This was our support. Do you want me to heat up your tea for you?

I decline but tell her it is delicious tea.

> Enjoy it (**noosh-e-jan**). Here, take some dates to sweeten it. Here, try one of these too, they're really delicious. Yeah, so that was our support.

I note that it seemed that with her husband, they were excellent sources of support for each other.

> Yeah. It was the two of us. Back in the day, my husband would always tell me to go out and enjoy myself. I would say no, without him, I didn't want to go anywhere. Yeah, it was my husband and I, just the two of us.
>
> In the beginning, when my son first went to school, things were hard. He had never had the experience of leaving home, and he didn't speak any English. He drove his teacher crazy. On a few occasions, he had escaped from the classroom window; they had to chase after him in the street. The second week the principal asked me to go to the school and act as a translator for my son in the classroom. I said I wouldn't be able to understand the teacher myself! The principal assured me that the directions I'd be translating would be simple. So, I went to his school for about one month. We didn't have a car at the time, and when I told the principal, she did something for me that… she was really, really an incredible woman. I really hope wherever she is, she's happy and healthy. She arranged for me to take the school van to the school with my son. Then one day she called me into her office and said it wasn't fair that I was going to school every day from morning to afternoon, and I was helping with everything for free, and so she hired me to work in the lunchroom. So, that's how it happened that I would first go to school with my son. Then when they didn't need me anymore in the classroom, then I would… (phone ringing)… then I would… (phone ringing)… then I would

> go to other classes and I would feed other children. (phone ringing)… ignore the phone… just forget it… I don't answer the phone anymore. (checks phone)… oh excuse me, it's my husband. I have to call my husband back. He worries about me… now that I've fallen into such a deep depression.

Here Ladan takes a few moments to call her husband back.

> Yeah, my husband worries about me. I don't leave the house. I just sit by myself in the dark. I used to go to work just to go to my son's graveyard during the break. That was my only reason for going to work… but then that became too hard for me. You know, seeing children that were just like him. I couldn't work there anymore. For so long, I felt like I was at war with the world to protect my son. I wasn't strong, I had thorns that stuck out of my body and protected my son from any harm. I had developed these thorns from the pain and injustice I had suffered across all our years.

I was alarmed by the extent of Ladan's depression. I spoke with her about the types of support she is now receiving to cope with her son's death. She assured me that she is seeking professional help in addition to receiving her husband's support. I provide her with information to seek counselling and make note to follow up to check on her. As I am leaving Ladan rushes to give me packages of nuts and sweets to take home from what I had enjoyed during our conversation. I insist that I appreciate the offer but again, knowing her act is *tarof*, I refuse. She insists, saying it has been months since they've had visitors, and she is happy to know someone enjoyed what she had in her home. I tell her that I will be back to go over aspects of the story and be sure she agrees with what I have written. She frowns and with a serious look says…

> Come back and we'll talk about other things. Anything. It will be nice to spend time together. But I hate saying the same thing twice, and I'm not repeating this story or hearing anything about it. I trust what you write. I don't want to talk about my story again.

She hands me the consent form and kisses me goodbye. As I leave, I feel grateful to have met such incredible women in the process of this study, but overwhelmed with the responsibility of finding ways of taking their stories beyond the dissertation to improve experiences of support for other immigrant women.

Creating Categories

In this section, I present the main conceptual themes that emerged from a synthesis of the narratives presented earlier in the chapter. I will explain the process that I used to group the narratives into major conceptual themes. Combined with the individual life-narratives, the overall analysis is meant to highlight the unique experiences of each Iranian immigrant mother who has a child with a disability, while highlighting similarities between the women's experiences. The process emphasized in this section, which creates an account of similarities across the experiences of the participants, is meant to provide an overall picture. Yet, I cannot emphasize enough that these common themes should in no way be used to boil these rich and unique perspectives down into "the" experience an Iranian mother of a child with a disability.

As a novice qualitative researcher, the process of data analysis seemed daunting. When all of the text was transcribed and translated, I restoried each woman's experience. I went through the process of member checking with each participant to ensure that the representations of the narratives were indeed co-constructions. The one to two page restoried descriptions of each narrative facilitated the process of categorization in two ways. Firstly, the process itself refamiliarized me with the text. Secondly, I felt secure in knowing that the interpretation of the narratives would not fall entirely on me. Although the process of data analysis is acknowledged as a process that reflects the views, questions, and biases of the researcher (DiCicco-Bloom & Crabtree, 2006), I felt that my approach added authenticity by providing a portion of each narrative in the participants' own voices.

I began by first classifying the data through focused coding. This process involved going through each participant's text line by line, and making notes about the main message being communicated. I then grouped the main activities/ideas into sub-categories, and then combined them into broad categories. The broad categories were initially descriptive, and provided an overall idea of the types of experiences that the women had. I moved from descriptive broad categories to more conceptual ones to get at a deeper understanding of the participants' experiences and to transform the data. The categories and conceptual themes were developed keeping in mind the research questions, which addressed the mothers' experiences as they related directly to their children. Other salient components of the women's stories, such as their internal battles with anger and depression were highlighted in the restoried accounts bearing in mind sociality, the personal and social, in a three-dimensional inquiry space (Connelly & Clandinin, 2006). The three major conceptual themes are illustrated in Figure 2 and include: interpreting and internalizing motherhood, managing systems of support, and success through education. The sub-themes dealt with ideas of maternal blame, responsibility and protection, creating and receiving support services, and valuing education.

Figure 2. Categories of Themes and Sub-themes from Narratives

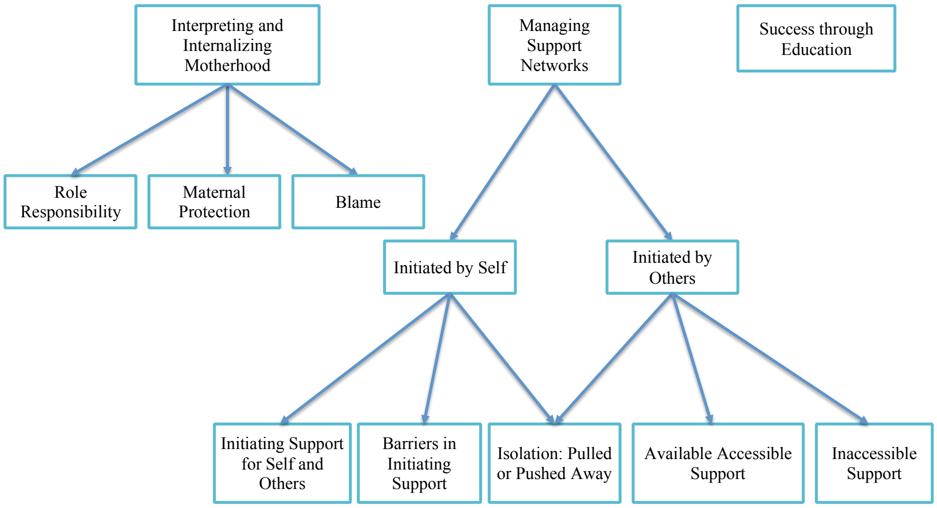

Figure 2. Themes and sub-themes developed from narratives of seven Iranian mothers of children with disabilities.

Interpreting and Internalizing Motherhood

Through the process of coding outlined above, I developed the conceptual categories that grew into major themes. The first theme, interpreting and internalizing motherhood, encompasses the sub-themes of role responsibility, blame and maternal protectiveness.

Role responsibility. One apparent sub-theme is the self and other-inflicted pressure that the women felt to take responsibility for their children's disability and for their protection. Defining and acknowledging the responsibilities of motherhood described one facet of this sub-theme. Simin and Parvin provided some illustrative insights.

Simin:

> Some people might think a good mother is someone who feeds, clothes, and gives their child a roof over their head. But in my opinion, this doesn't make a good mother. A good mother is someone who sets her child on a good path, on a path for success, right from childhood. That's a good mother. Not someone who gives their child the necessities.
>
> … Maybe someone who sees me from the outside would say 'you're a very good mother' but I still haven't been able to give my child the kind of service that I would like – because of the family problems that I have with my husband… Everyone tells me I'm a good mother, but I say, no I'm not good because I **can't**- not that I don't want to- but I don't have **time** for my children. I don't have time! It's one of the worst things that people tell me I'm strong. Just think about the fact that this mother is pulling herself along just for her children. Otherwise I'm a person too, you know!

Parvin:

> A lot of mothers are at home and they're able to put the time with their children and take them out. I'm always out and in reality, I'm the breadwinner of the family. As a woman who works outside the home, it's really interesting that I'm still expected to be a mother. A housewife. When in reality, I'm not a housewife!
>
> … But I don't accept the image society has of a woman. I even question motherhood itself. I believe that I'm able to replace my role with that of my husband and become the provider and I don't blame him for this switch. My doctor says: "you've accepted this, but as an Eastern man, he now sees himself in

> a position of weakness. He's lost his power and in his way he blames you saying you're not an adequate housewife or mother."

The women were receiving messages about their roles and responsibilities as mothers, and, five of the seven mothers described the impact that these messages had on their lives. Ladan and Fataneh were the least vocal about the expectation to fulfill responsibilities of motherhood. Both women suggested that they were in warm and supportive relationships with their spouses. The women each accepted roles that were described by others as "maternal"; Fataneh left her position as a full-time accountant to volunteer at her son's school and to learn about how to best support children with Autism Spectrum Disorders. Ladan also dedicated her time to working with her son, first volunteering in his classroom to provide additional support, and later working as a classroom aide to support other students in her son's school. Ladan and Fataneh described the decision to spend more time with their children as a collective one, made with their spouses. They actively spoke of the value of their husband's contributions both to their child's development and to their own emotional well-being.

Blame. The women in the study described receiving message of blame for their child's disability from their spouses and outsiders. These messages were internalized by the women who believed they weren't adequately fulfilling the roles and responsibilities of motherhood. This category is best conceptualized as the blame and stigma the mothers experienced as a result of their child's disability.

There is a significant portion of every mother's narrative that is linked to an experience of mother blame. This is perhaps most evident in the stories of Banoo and

Dana, whose children were diagnosed with schizophrenia, and Ladan whose child had a physical disability.

The mother blame in Banoo's narrative was evident from the start, where she described how service providers and family members had blamed her for her daughter's diagnosis, and how her son had later blamed her for his own diagnosis. She described, toward the end of her narrative, the ways in which she has internalized this blame.

Banoo:

> Our friends told us not to disagree with her, to give her what she wanted and not be too hard on her. And well, sometimes I think that maybe we were too hard on her. Maybe if we had gone easier on her, things wouldn't have turned out this way. And then I think, well maybe if my daughter hadn't developed this problem then it wouldn't have happened to my son too. And I still believe that. I think it's possible that with a better environment, he wouldn't have turned out this way. … And me… well for example… my daughter… I tell myself, if we had normal living conditions and things were calm, maybe she would have stayed normal too. But our circumstances were different… we were under a lot of stress. And well, this stress was a result of both the war in Iran, and a volatile relationship between her father and myself. So she couldn't handle all of this. That's how I picture it. … My problem is that my son says… you know... he says yeah, I got sick. My environment was bad. It's your fault that I got sick. You made me sick. It's my sister's fault that I'm sick.

Dana's experiences of blame for her child's disability were similar to Banoo's. However, Dana also received messages of blame from service providers. The hospital in Toronto where Dana's daughter was staying had named Dana as a trigger for her daughter's violent behaviour. In Dana's narrative, service-providers in the hospital focused on how she negatively influenced her daughter's behaviour but not on how external factors, such as living through war in Iran, were involved.

Dana:

> … She was our first child, so we didn't have any experience to know if the way she was reacting was normal. And in the hospitals they look at you in some way as if you're trying to avoid their questions. And I can't say that the context under which this child was raised was really normal. Then they look at me as if I'm trying to lie to them.
>
> … For 22 days, my child was locked up there… restrained… and I didn't have the right to see her… because they had simply written that it was a safety issue. They said I was a trigger for her behaviour. What are they saying? They're basically telling me that if I were dead, my child would be better off.

Part of Dana's narrative also illustrated the ways in which she had internalized this blame, and how she attributed her daughter's lack of verbal communication as a sign that she had failed as a mother. She compares herself to Banoo to illustrate this point.

> And really, Banoo's daughter has a special quality… and I really admire her mother for it… I'm sure she's learned many things from her mother. Her daughter explains things. She speaks. But my daughter, for example, doesn't speak at all. She can't express her needs.

Unlike Dana and Banoo whose experiences of blame were mostly implicit throughout their narratives, Parvin acknowledged her experiences of mother blame openly. As the sole breadwinner in her family, she spent a great deal of time working outside the home. Her husband viewed her work as the source of their children's difficulties, and her son attributed her approach as a mother as the source of his anxiety and social isolation.

Parvin:

> My husband blames me a lot. He says if I had put more time with our son, he wouldn't have turned out this way.
>
> … Sometimes I think maybe the only mothers that are successful are those who sit at home and just put all their attention on their children. And well I hear all the blame for it now. And when there's blame, there's argument, and when there's argument, the child hears.
>
> … Yesterday my son said: "You know what? You didn't raise me like a strong boy. You cuddled me a lot and raised me like a little girl, and I have this girly attitude"… I keep working on my son, trying to prepare his thinking so when he gets married, he'll be capable of respecting his partner. But what's interesting for me is that in all this, he's blaming me. This was interesting for me. You know what? Either his problems are something genetic that have come from me, or I haven't raised him right.

Simin was the least vocal about implicitly or explicitly experiencing blame for her children's disabilities. Her narrative highlighted her sense of maternal responsibility and her inability to provide for her children because of external factors such as her husband's mental illness, inadequate systems of formal support, and social isolation.

Maternal protectiveness. External sources of blame often led the mothers to find ways to protect themselves, their children, and their families. This sub-theme was most evident in Ladan's narrative, where she describes protecting her son from the abuse and discrimination that he faced in respite and daycare centres. In her narrative, Ladan explained that her son had been tied to a chair in daycare, physically abused by a service-provider in a group home, and was routinely asked to leave restaurants and other public spaces. I sensed her enduring protective nature even years after her son had passed away.

She was hesitant to open up and to speak about him but she ended our conversation with this poignant statement:

> For so long, I felt like I was at war with the world to protect my son. I wasn't strong. I had just thorns that stuck out of my body and protected my son from any harm. I had developed these thorns from the pain and injustice I had suffered across all our years.

Ladan was forgiving of the stigma that she and her son had experienced, attributing it largely to ignorance, but she continued to fight it to protect her son, even after his death.

Other participants explicitly described the ways in which they worked to protect themselves and their children from harm. This is perhaps the most evident with Ziba, a woman whose child was the result of an extra-marital affair. She isolated herself to protect her child from ridicule, anticipating that others might associate her child's diagnosis with punishment for her relationship.

Ziba:

> And now they'll say what happened is good because what goes around comes around. They'll say: "She went to screw with some guy's wife, so God punished her by putting this kind of child in her lap." You know? Well, these are the kinds

> of things they say! I already know what they'll say! Well why? What's the reason that I have to take my son to these places to have people laugh at my son? They'll say: "the child is a bastard... his mom is…" you know? Do you know what I mean? Well, I'm not proud of what I did, but I don't agree with what they say. So I have to protect my child… I don't want to take him somewhere where people will humiliate him.

The stigma Ziba experienced appeared to be her greatest personal challenge. This message was evident throughout her narrative, where she described at length the ways in which she stopped communicating with family and friends, in order to protect her child.

Managing Support Networks

The second theme that emerged from the narratives is managing support networks. These networks were either created or removed by the women themselves, or by others in their environment, such as family members, friends and service providers. When others created the networks, the women described them as successful and accessible, or available but inaccessible due to various linguistic, cultural or logistical barriers. The women also all described feeling isolated due to stigma or shame in the community. These feelings of isolation can be attributed to the process of either pulling away or being pushed away from others in the community.

Accessible support. The seven women interviewed all expressed positive experiences of professional support from services providers, while only two of the seven, Ladan and Fataneh, also described receiving positive emotional or moral support in Canada.

Ziba and Banoo expressed the most positive overall experiences of support with service providers. Ziba's narrative outlined the ways in which service providers had guided her in accessing multiple services for her son, but had also served as a source of emotional and financial support.

Ziba:

> … my son's hospital introduced this last organization that I'm now in touch with; they even filled out the forms for me, and put me on a waiting list of 9 months. Through them we got a worker, who was such a wonderful woman… and from there they took my son out of the waiting list and registered him for senior kindergarten at his current school. This worker who was now coming was really supporting both of us. If I was upset about something, I could speak with her… I would call her… if I needed to go to court she would come with me, if… for example, I needed to go somewhere I could ask and they would come with me… they would accompany me so that I wouldn't get frustrated alone. They helped me in many ways. Now even when my son leaves the school, the workers will still be there to help us… if we're low on food, they show us where the nearest food bank is, if we need financial support for disability-specific services, they connect us with the appropriate organizations.

Banoo had similar experiences of support with hospital staff members who helped her find a suitable living arrangement for her daughter that focused on independent living skills:

> … one day my daughter's doctor recommended a group in the hospital where she had her folder. Her doctor said they would help patients keep track of their

> medication, help them find accommodations… and basically give them any support they need. We were so fortunate to receive this support. My daughter joined this group and they reached the conclusion there that she really just can't live with anyone. Through them she was able to find an apartment to live and she now lives on her own but visits the program at the hospital twice a week, they see her, give her medication and her injection. If she doesn't go one week, they come to her house and ask why she didn't go. Here, I don't have any family or friends… nothing. So I call the group and tell the nurse: "I call my daughter's house, but she's not there." The nurse says: "okay don't worry, we'll go to her house now… or we'll call the police and see if they can help us." They follow up right away.

Although the majority of the mothers described some experiences of positive professional support in Toronto, very few described having their emotional needs met by others.

In addition to Ziba who received emotional support from service providers, Ladan and Fataneh were the only two of the seven participants who had positive experiences of emotional support in Toronto. To Ladan, her husband was a significant source of emotional support, especially during a time when she was in a deep depression due to the death of her son. She described her emotional connection with her husband as a lifeline that kept her from taking her own life.

> My husband is an incredible and generous man. He's been my biggest support, and he's the reason that I keep myself here. Since my son's death, I have a really

> hard time wanting to go on. The only reason I keep myself here is for my husband. He keeps me going.

I was alarmed by the comments made by Ladan and confirmed that she was receiving outside professional support for her own emotional well-being since the passing of her son. I also phoned her the following day to check how she was doing following such an emotional interview and to provide her with additional resources on seeking mental health counselling in Toronto. She explained that throughout the process of immigration, acculturation, and the navigation of the service-delivery system, her husband had been her strongest source of emotional and financial support.

Fataneh, whose young son was diagnosed with an Autism Spectrum Disorder, had sisters and a supportive husband in Toronto and was the only participant to describe multiple sources of emotional support in Canada.

> In this time I also met my husband. My husband is an incredibly good man. He always tells me that my son is the biggest challenge I'll face in my life… and I need to find the best way of working with this challenge.
>
> … I used to cry often and speak a lot to my oldest sister. She would always say something interesting to me… she would say all children are the same. She wanted to give me this type of support, to say don't worry, all children are the same.

Finally, other women, such as Ziba and Simin maintained that, while they were not receiving positive emotional support in Toronto, they occasionally received long-distance support from family members:

Ziba:

> My family helped me a lot. Thankfully my family is relatively open-minded. Eh… they weren't happy about the situation, but they always supported me. So far I've gone to Europe three times to visit them, and they shower my child with love. My mom, dad, brother, sister… ouf… he's like the only grandchild, he's spoiled.

Inaccessible support. Although some women noted experiences of successful and accessible support, especially from service providers, other women expressed disappointment in the services available. The sentiments of disappointment were generally related to services becoming inaccessible due to cultural or linguistic barriers, as described in Simin's narrative, or because the services, intended as support, were in fact harmful for the participants, as highlighted in both Dana and Ladan's narratives.

Overall, the participants appeared to have gained quite a bit of expertise regarding the sources of support for children with disabilities and their families in Canada. However, they noted that as newcomers they had known very little about the services available in Canada and were frustrated about the challenges that they faced when navigating the service delivery system. These frustrations can be divided into four categories (a) support was not available due to service-providers and acquaintances who did not *provide* accurate or sufficient information, (b) support was not available due to a system that is more reactive than proactive, (c) support *was* available but inaccessible due to language and cultural barriers or time constraints, and (d) support *was* available, but did not address the mothers' needs.

Insufficient support from service provders. Simin illustrates the frustrations she experienced in her interactions with service providers, who believed she was lying and didn't understand the degree of help she required.

Simin:

> Look, in Canada, there's a lot of opportunity. But unfortunately in the Iranian community most people don't make use of these services. I think people who work in this field should really be people, who give correct answers, when newcomers like me have a question. I think it's so nice when people who want to go into this field of work really love what they do. That way, they'll be quick to give tell us what services are available to us. Because I've seen some service providers say "this person doesn't need anything" or "maybe she's lying". Everyone puts on a mask, sits down, and tells you nonsense as if they know everything. If I didn't know better, I would have believed a lot of the things people told me. I speak of my experiences so openly because I want this thing that happened to me, these mistakes that I made, I don't want them to happen to anyone else! If we can have a warm community and all help each other… we'll all suddenly see that we were all able to pull ourselves up and out of bad situations.

Support reactive not proactive. Simin described how support could be more efficient or effective if service-providers would react immediately instead of waiting for the situation to become dangerous.

Simin:

> The frustrating thing is if I cry, or if I hurt myself, or take pills to kill myself, then they'll come help me. Or if I say: "yes yes, he hit me! He hit me and my kids!"

> instead of being proactive so that a dangerous situation doesn't come up, they're waiting for it to happen so then they can say: this person is dangerous.
>
> … But people say, since she doesn't cry and hasn't yet died, then maybe she's not a very important case. This world is so twisted. I wish that one day, everyone, everywhere, would take responsibility

Banoo also struggled to find adequate support for her son, whose behaviour caused significantly fewer problems than her daughter's. Banoo believed that her daughter's difficult character worked to her advantage, as she was able to receive more targeted supports.

> My biggest concern is now my son. He was always a warm and kind child, so I didn't have the same problems trying to separate him from myself as I did with my daughter. Unfortunately now he's developed a strong attachment to me and he doesn't leave the home. What I am trying to find for my son, is a way to integrate into society and develop independence.

Support uaccessible due to language and cultural barriers. Simin and Dana both described the cultural and linguistic barriers they experienced in communicating with service-providers.

Simin:

> Well, when I was pregnant I used services that were for pregnant women – but then again I found out about these services when I was pregnant with my last child. Well no, I would go to the classes during my first two pregnancies too but because my English wasn't really good, I didn't understand what the woman was saying at all.

> ...But well, my language skills had improved, I understood a bit. But if you want the truth, sometimes I didn't let on that I didn't understand anything. They didn't have translators there.

Dana:

> You know, this war is something that only we can understand… and unfortunately it's something that here, when we try to talk about it in the hospital, they show no emotional reaction. No matter how many times we say, in Tehran we were continually the faced with bombings… These people here, when you try to explain the circumstances to them, they just don't understand! I've had so much trouble over just this. And then they speak to me in a way… they completely accuse me of changing my words and being inconsistent… They basically ignore completely… this is a cultural barrier and language barrier.

In addition to problems with language and culture, participants faced difficulty accessing services because of cultural differences accessing support.

Simin:

> My sister won't accept that she needs to see a psychiatrist. She says: "what will people say?" or "if my husband finds out I've gone to see a psychiatrist he'll say, the lady's gone crazy and she's needed to see a psychiatrist." But me, in this country, you know what? I say I'm free! I can go talk to someone about my problems if I need to. But my husband turned around and said: "where do you think you're going? Tomorrow everyone will be talking about you. They'll make fun of the kids and say their mom is crazy and they'll take them away from you."

> I said: “What do you mean? You think I’m crazy? I’m preventing my problems from getting worse!”

Parvin:

> Husbands usually believe that it’s not working and if you have to see a psychiatrist then you’re crazy and they’re crazier than you are. That’s why we went for a few sessions and then we stopped going. But now again since last year I got a letter from his grade six teacher that things are like this, like that, again with a lot of convincing I took him to our family doctor.
>
> But for a while, our friends would say ignore the problems, they’ll go away on their own. In our culture these things exist… they say: “well, he’s just a child!” or my husband will say: “You’re being too hard on him. This is normal.” In reality it’s like I’m protecting them in a way. I’ve always gone to seek help, and I’m still in the process of seeking help.

Banoo:

> In the hospital they had told her great things about group homes, and they had given us the address to three downtown. And so we went, the three of us (my daughter, my husband and me).... The three of us took her suitcases and went to a group home. We were immediately shocked! Group homes are terrible places! Especially for us, with our culture. So we told my daughter that the home wasn’t an appropriate place for her.

Support available, but inadequate in addressing needs. This barrier in accessing support was the most significantly addressed by the women in the study. Most participants described how when services were available, they weren't effective in meeting their pressing needs.

Simin:

> I can say that the only services I've received are in reality a way to pass time. They just do something so their client doesn't suddenly go crazy with depression. Just think about the fact that this mother is pulling herself along just for her children. Otherwise I'm a person too, you know! This child has this problem, the husband has his own issues, we have problems with income, problems of isolation, problems of I don't know what…. But people say, since she doesn't cry and hasn't yet died, then maybe she's not a very important case.
>
> When mothers give birth here, after the birth they come and ask if you would like a nurse to come and see you. I said yes. Because… I didn't have any support at home… I assumed they meant someone would come to my home and physically help me. After they came, I saw that no…they have a different plan. They were only coming to answer any questions I might have.

In their narratives, Dana and Fataneh described experiences intended as support that could be harmful for their families. By trusting professionals as a new immigrant, when she didn't understand how to navigate the service-delivery system, Dana noted the harmful practices that had long-term negative effects on her family's quality of life.

Dana:

> The first thing they did at the hospital is they put the label of schizo on her. I wish they hadn't. I wish she had received a proper assessment right from the

> beginning… because at the time, I wasn't really fluent in English, and I wasn't familiar with the system. And when I look back, I realize how quickly they put some labels and diagnoses on her that I now find unbelievable. You know I wasn't able to read at all…Yeah, after that she went to another hospital and they diagnosed her as bi-polar and said she had a personality disorder too, and they just gave her a series of varied diagnoses. They have given my child 15 diagnoses until now.

In addition to receiving 15 diagnoses that remain in Dana's daughter's medical files, her daughter received her first criminal charge in the hospital and was locked up in the hospital room. Dana describes feeling powerless after following protocol to receive support for her daughter that was ineffective.

> One day she pushed her caregiver and they took her to the hospital and put her in the mental health unit. She really wasn't fit for that unit. She couldn't speak, she couldn't make any connections… she couldn't do anything. The first thing they did in the hospital was they threw her… they locked her up. They threw her in a room. She didn't have water. She didn't have a washroom. She had nothing. She was there for three and a half months. And there, she couldn't even ask that they turn the light on for her. **Twenty** minutes was all my child was allowed to come out of the room, and even then three security guards would accompany her.
>
> I have all the letters. I would beg them and say: "please let my child feel calm for the half hour that she's allowed out of the room." But when the security would come, they would yell at her and sit and laugh amongst themselves. I had made notes of everything… I've written it all down. So I took it when we had our

> meeting for the crisis intervention plan and asked that they explain the conditions in the hospital. They told me they couldn't do anything about it. They told me to send a letter to the director of their unit. So I did as they asked and nothing happened. There was no point.

Fataneh's felt that her son did not receive adequate support in the regular French immersion system, and she was frustrated with the low academic expectations placed on her son given that his challenges were social skills and and not academic.

> They said there was a class there where my son could be well integrated. So we went to visit one day. I went on my own and I saw that all the children seemed to be delayed. For example, it was a grade four class, but they were working on grade one material. But they all looked normal, and their teacher was very nice. Then I told the teacher right there that my child doesn't have any of these same problems – it's true that he has social problems, which they had too, but doesn't have academic problems. If he comes to this school, he'll be bored.
> …We realized things were becoming too difficult so the next year we put him in an English school and told them about some of the challenges he has and got him and educational assistant. Things weren't great there either. The educational assistant was a man, an old man, who acted exactly like his slave! I would come home and see that the man had done his homework for him… he would say the words, and the old man would write them.
>
> … I became involved in classes to learn how to best work with my child. Since last year, I've been going to their school library and working once a week. But then if my son bothered anyone even a little bit, he was brought to the library. I

> finally asked why they would always bring him to me; I thought they should ask him to go to the library on his own to get a book and come back, he has the librarian for support.

Finally, when participants did find ways of navigating the support services, they often experienced other barriers related to services that were financially or logistically inaccessible.

Simin:

> With all these problems, how am I supposed to sit and do speech therapy with my child? Everyone tells me I'm a good mother, but I say, no I'm not good because I **can't**, not that I don't want to, but I don't have **time** for my children. I don't have time!

Parvin:

> I really notice something lacking in this system: really, not everyone is able to pay $150-$200 an hour to a psychiatrist for help. And old-fashioned psychiatrists are much better in their practice than newer ones. The person that I used to see would spend an hour and fifteen minutes with me each time that I saw him. He was over 80 years old and had spent over 40 years practicing. He would help you get to know yourself. I'm not looking for someone to see and to speak with. But you know, not everyone can afford this. What I was using before was covered by OHIP and that was really good for me.

For Ziba, financial support was minimal and the process to obtain it was frustrating. The father of her child was a millionaire who initially refused to provide financial support. To make ends meet, Ziba was putting expenses that were not covered by welfare on her credit card. After convincing her husband to provide some additional funds for child support, Ziba was disappointed to discover that her social assistance was subsequently reduced. In this way, Ziba believed that the system was set up to keep her in poverty.

Financial resources were also limited for Simin, who like Ziba, was receiving monthly welfare cheques. Simin's main concern was with the lack of support that she received for her husband's mental health and addiction problems. The little money that she received from the government was essential for her family, and she described the importance of immediately using it for necessities such as food, to avoid having it spent on drugs.

> We don't have access to a car, so something like grocery shopping in the snow can be a challenge. After receiving our welfare cheque, I go to the grocery store and spend everything on food. I know if my husband gets his hands on it, he'll spend it all on drugs – so I have to make sure I spend all the money at once. And then I have to push it all back by myself in the snow. Even these things can be exhausting.

Isolation: Pulled or pushed away. The probes I used during the interview did not address various types of support described above, nor did they cover whether the support had been adequate or insufficient. The participants' narratives, however, guided the definition of support as well as the extent to which the supports were found to be accessible or useful. In addition to experiences of support, various rich descriptions of social isolation emerged from the narratives with participants either being pushed away or willingly pulling away from others in the community.

Pushed away. The narratives of Ladan and Banoo highlighted experiences of social isolation that resulted from the stigma and rejection from friends, family and community members. Banoo's experiences with family and friends were isolating, as they chastised her for contributing to her child's disability.

Banoo:

> Unfortunately this sickness is so taboo that you can't even talk to your friends about your problems. Actually most people assumed that there must be something wrong with us, that we must have done something to our daughter for her to turn out this way.
>
> So in the end they assumed that we must have done something wrong for her to end up like this. Nobody really knows much about this sickness to come and empathize with us. Everyone wants to give us advice, or they want to complain to us. When she was first starting to act out in Iran, I took her to the doctor who scolded me for wanting to medicate such a young woman.

Ladan:

> My mother-in-law couldn't accept that our child had problems. And on top of that, she really wasn't the kind of person who would want to take care of her grandchildren. My father didn't like my child at all. He would say, it's because I love you so much… He would say: "I can see that your child upsets you, and I see your sadness, and it makes me dislike your son."

Pulled away. Ladan also distanced herself from individuals and situations that were the sources of the abuse and stigma experienced by her family. Like many of the other participants, this distance inadvertently isolated Ladan and her family.

Ladan:

> I didn't go to parties where there would be people we didn't know. The thing that was really hard for me to take was all their questioning. If nobody asked me any questions, I would have been okay with it. But they would start asking me questions, and they would take me back. You know? Back to the early days. And this would make me feel bad. I wouldn't talk much because I knew they didn't have the knowledge to help me, or the experience to know what I was going through (**ham-pa**). They would only upset me more. They would ask a lot of questions, but they would also give their opinion. They would just tell me what they thought, you know what I mean? (Exaggerated sweet voice) "Did you eat anything that was bad for you during your pregnancy?" It was then that I wanted to tear them apart with my nails. Do you know what I mean?

Like Ladan, other participants expressed pulling away from their family and acquaintances as a way to protect themselves and their children from harm. This is perhaps the most evident with Ziba, a woman whose child was the result of an extra-marital affair. She isolated herself to protect her child from ridicule, anticipating that others might associate her child's diagnosis with punishment for her relationship.

Ziba:

> I don't like it at all! Because … they would say: "the girl got pregnant! Look at her! With a bastard child! And look the child has problems and she's kept him.

> Young woman, do you not have a brain? Why didn't you get an abortion?" You know? When I started hearing these things, I pulled myself out of the Iranian community.

Ziba's isolation appeared to be her greatest personal challenge, and was evident throughout her narrative.

In contrast to the women described above, whose children were diagnosed with disabilities, the two women whose children were diagnosed with schizophrenia did not believe that the presence of more friends or family would be a better source of support. Banoo attributed this to the stigma associated with mental illness that isolated them even from people closest to them. For example, she describes the way that her daughter threatened to shame her in front of friends and family as a way to illustrate her dissatisfaction in arguments.

Banoo:

> It might have helped my son to have family here. But my daughter… it just so happens that one of my closest friends lives here. She once found my friends' number and called her a few times initially just to chat. Then she started calling and bothering her. Each time we got into a fight, she would threaten to call my friend and embarrass me… because she knew my friends didn't know that my children were sick. So I would say… fine… go ahead… if you want to call, then do it. So she would call my friend and scream: "send your sons to come kill my mom!" She was driving my friend crazy. So I think if I would have family here, I'd have to make sure they weren't in touch with my daughter. Because I think through them, she would have started a world war with me… she wanted to have

> everyone against me… she'd always tell people to come and kill me. I have a sister who lives overseas, and when my daughter gets in a fight with me, she calls her too and swears at my sister's entire family. She does it to bother me, because she knows I get really upset when she does this.

For Banoo, the stigma and shame associated with mental illness isolated her from even the closest of family and friends. She kept the diagnoses a secret and felt that the distance reduced the likelihood that others would be bothered by her problem, that she would be shamed, or that she would be discovered.

The complexities of isolation: Pushing and pulling away. In many of the narratives, the participants clearly indicated whether they had actively pulled away or had been rejected from the community by family and friends as a result of their child's diagnosis. However, in reality the women's experiences are much more complex and cannot be categorized by such a clear-cut distinction; often the fear of being pushed away from family or community members resulted in the women proactively pulling themselves away. This is best illustrated through Simin's narrative below.

Simin:

> Because of the problem that he has, we have to keep ourselves far from people, because if someone finds out, they pull themselves away from us. Look, I don't want to be ostracized. But my friend has a healthy husband, and they live together. One day she comes to my house she looks around and finds out my husband is a drug addict. She won't come back to my house again. She'll cut off all contact with me, because she'll think about it and worry that maybe her own husband will be influenced by mine. She'll also wonder: what does this person

> have for me to learn from? And really, what does he have? So I try to keep my problem for myself.

Initiating support for self and others. Where there were no existing or adequate sources or structures of support, the women in the study created or sought ways to initiate them. Dana, Ladan and Fataneh all changed their own career paths in order to better understand their child's disability and to create support within their family unit. For example, when she first arrived in Canada, Ladan accompanied her son to school to support him in his learning, and eventually became a lunchroom monitor and finally an educational assistant. When she wasn't in her own child's classroom, she was working with other children to better understand the service-delivery system in Ontario. Similar to Ladan, Fataneh sought ways to support her family by leaving her position as an accountant, devoting her time to being a stay-at-home mom and to attending workshops and support groups to better understand her child's disability. She also spent her time volunteering at her son's school, not only to better understand the system in Ontario, but to ensure that she had a voice in her son's academic outcomes. Finally, Dana who was her daughter's sole caregiver, earned a college degree in behavioural therapy after her daughter was diagnosed with schizophrenia. She changed her field of study to better understand how to respond to her daughter at home and in the community, but later found herself becoming an advocate for her child and for other Iranians with schizophrenia in Toronto. A big part of Dana's narrative addressed her desire to create support outside of her family unit for others who were in similar circumstances.

Other participants found alternative ways of addressing their need for support in the community. By participating in this study and by sharing their narratives, Banoo and

Simin were finding a way of making change in the community. Both women adamantly refused compensation and explained that, to them, their participation was intended to spread awareness about the isolation and lack of support faced by many Iranians in Toronto dealing with mental illness. Although Simin's children were both diagnosed with disabilities, her main concern, and the source of her social isolation, was dealing with mental illness and addiction.

Parvin had found ways of addressing the needs of others in the community by setting up a support group for newcomer Iranian mothers in London, ON. She found ways of supporting women based on their needs by connecting them to service-providers in their area. Though she had not yet created a similar support group in Toronto, she had joined other organizations of Iranian women. Many of the women described the need for an organization or a group home that would welcome and support their children and their families. Dana and Banoo were working with a number of other families to create a group home for Iranian children with schizophrenia, and Parvin highlighted the value of having workshops for families to better understand how to access government financial support and services in Canada. Simin's desire to help others was in the transmission of information; her goal was to support other newcomers by providing them with information about the resources and governmental support that was available in Toronto.

Ladan, who was mourning the loss of her son did not address creating systems of support, and Ziba, who felt rejected by the Iranian community believed that her greatest source of support was others who had accepted her past and who supported her despite her extra-marital affair that resulted in a pregnancy.

Barriers in initiating support. Many of the mothers described experiences where they had attempted to initiate or create their own sources of support in Canada, but were subsequently faced with numerous barriers. These barriers involved difficulties with acquiring visas for family members who could visit and provide emotional support, restrictions or challenges in creating culturally-sensitive services for Iranian families, and limitations in accessing support for their children in school.

Parvin and Simin described their mothers and sisters who are currently living in Iran or Europe as potential sources of emotional support and longed to have them in Toronto. Although Ziba had described some positive experiences of long-distance family support, she too felt that she required her parent's support in Toronto.

Ziba:

> Yeah… you know, if I had my parents here, there is no question that I would have had an abortion. Yeah, because… well, the reason I didn't have one was that… eh… I was alone. There was no help… and I hadn't told anybody that I was pregnant and I really had to make the decision completely on my own. Well if you're able to speak with someone about your decisions, each person has their own opinion… you know? At the end of the day, you have your dad, your mom… you're not alone if you want to do anything. I was really scared. I was terrified.

Parvin:

> You see, here, in our loneliness, our children only receive affection from us parents. There are no aunts or grandparents. I am really attached to my family, and even after 14-15 years, I'm still homesick. If they were here, I would have a whole other kind of emotional support.

Fataneh described her frustration in attempting to receive adequate educational support for her school in the French immersion system in Toronto. When she questioned her son's principal about getting an educational assistant for her son, she was told that it would not be possible in the French system. She then attempted to use her own resources to better meet her son's educational needs.

> The principal kept saying French immersion didn't have the budget for this type of support; they insisted they weren't trying to argue with us. So I said I would hire someone myself and pay them out of my own pocket so that they could work with my child as an Educational Assistant in the classroom. The principal said this wasn't possible.

Finally, Dana went to great lengths to find ways of creating support networks for Iranians with mental illnesses and for a centre where services and resources could be provided in Farsi. She found herself faced with numerous roadblocks:

> For three years, I went to every civic centre around here to see what the regulation would be if I wanted to set up a group home. None of these civic centres would give me any information. From there they told me I had to go to city hall. I went there and they told me I had to buy a place and they would determine the zoning. But I was thinking… I don't really have to buy! So I asked, do I really need to buy something? They said yes. Then we got all our families together (there's a lot of us!) and we thought we could pool all our money and buy a house together to see if we can get a license. We spoke with a few organizations and realized that we couldn't. Our problem was, see… within the Italian community for example, they have a secular church who gathers people and funds and goes to the embassy

> to get support for people within their community in need. But us, who are we supposed to go to? The Iranian embassy? You want us to go to people and ask for support? Until today all of us have learned to hide our children's disabilities and mental illness… in our community, we see this as a source of shame. Well see, many of the problems that we have now... the system doesn't formally recognize us, our culture and our language. What I'm trying to say is, this lack of support is in our community, in the Afghani, and Tajik communities as well. If you found a single community based location… there are none! I studied in college, and in our college I couldn't get funding. So I was talking to one of our professors who said for children who are diagnosed with an Autism spectrum disorder, there's a chance to receive funding. But for others, I really don't know. And you know, here, hidden information is golden.

Participants interested in creating systems of support were therefore faced with a number of systemic, structural and institutional barriers, including difficulty obtaining VISAs for family members, difficulty implementing a support group for the community, and challenges meeting their children's educational needs.

Success Through Education

When women faced barriers accessing support, they believed that the right information or knowledge could reduce their challenges. Dana's statement that "information is golden" was echoed in some form by all women who participated in the study. They stressed the importance of positive learning opportunities for their children, and they sought ways of educating themselves about disability policies and services. Some of the ways that the women worked to educate themselves about their child's exceptionality has been addressed in the previous theme regarding how the women were initiating systems of support for themselves and others. Some participants were explicit in their statements that education would lead their family and their children to positive outcomes.

Dana:

> Since we couldn't get her the types of services that she really needed. I changed my field and studied behavioural science/behavioural therapy and I started working with children who have an Autism Spectrum Disorder, and through my work I learned how to manage situations with my child at home. I worked in a group home, and did art therapy and used picture exchange communication systems and so I learned everything at work.

Parvin:

> The children with difficulties should be identified, and they should receive help in schools. Exactly like what happened to me… although I was the kind of person who went to them and asked for help. Us Iranians, all we care about are the terms of education. As long as the child becomes a doctor or engineer…. I'm one of those people. Aside from what I did for my daughter, I told her even if tomorrow you want to go flip hamburgers or if you want to go mop floors, that's your choice… but first you have to get your PhD, in any field that you'd like. I really believe in this. I think it's the key. That's why I want schools to be more involved when there are problems; because either families ignore the problems, or they can't afford to deal with them, or they don't have the time to take their child to a counsellor or a doctor.

Ziba worried about her son's educational future:

> These children… they can't write essays. So the majority of them can't go to college or university because of the challenges they have. Unless they have a lot of support, but even then, they have limitations with which fields they can study. They don't have leadership skills. They can't ever be in management or in higher degrees.

Ziba's worry about her child's future educational achievement, Parvin's emphasis on education as a successful outcome and Dana's initiative to change her own educational path to support her child all illustrate the way the mothers valued education as a means of achieving success, or as their definition of success in itself. This theme was not discussed in isolation of the other two themes that emerged; to some degree, the three overall themes were interconnected. The women's interpretation of their roles as mothers led them to take initiative and seek and manage support services for their children with disabilities. When these services were not adequately available, the mothers took the intiative to create their own systems of support and in many instances, they believed this could be done through education.

Although the themes and sub-themes relating to the role of motherhood, education and support emerged from the seven narratives and provide an overall picture of the experiences of the women who participated in the study, there was a significant amount of variation in each woman's narrative. By using narrative inquiry as a methodology the women's voices were honoured and the diversity of their perspectives were illustrated. The following section will discuss the diversity of individual narratives in the frame of Bronfenbrenner's Person Process Context Time theory (Bronfenbrenner & Morris, 2006), followed by a discussion of the ways the themes and sub-themes are addressed in the literature.

CHAPTER FIVE: DISCUSSION

This study explored complexities of Iranian women's lives and, in particular, examined the experiences of immigrant Iranian mothers who have a child with a disability in Toronto, Ontario, Canada. Bronfenbrenner's PPCT developmental framework was used to frame these women's experiences and account for the various individual, contextual and temporal factors that impacted their experiences (Bronfenbrenner & Morris, 2006).

Revisiting Bronfenbrenner's Developmental Framework

Contextualizing the data by restorying the narratives and by categorizing the data into themes and sub-themes underscored the complexity of each of the individual women's experiences. The support available in Canada to each of the participants, as well as their fears regarding their children's futures depended on various person, context and time factors that were unique to each individual. These factors included the length of time that the family was living in Toronto, financial resources, the support of a spouse, availability of family and friends in Toronto, the child's disability, the nature of the support services available for the exceptionality as well as the developmental age of both the mother and child. Contextual components of influence also included public policy, views of disability in Toronto and in the city's Iranian community, and formal and informal support networks. Bronfenbrenner's PPCT theory provides a framework that draws the themes into the literature while maintaining the integrity of each individual narrative. The following section will address the ways in which the mothers' experiences fit into Bronfenbrenner's PPCT developmental framework before addressing the themes and sub-themes of the narratives.

Individual proximal processes. Proximal processes refer to interactions between the organism and environment, and are the primary mechanisms producing human development. These processes occur between an active, evolving person and the people and objects in his or her immediate external environment. To be effective, the interaction must occur on a fairly regular basis over extended periods of time (Bronfenbrenner & Morris, 2006).

These proximal processes can involve group activities, such as understanding the process of service delivery in Toronto through interactions with friends, family and service providers. They can also involve solitary activities such as a mother coming to understand more about her child's disability and how to navigate the service-delivery system in Toronto by actively seeking information online. In this theory, Bronfenrenner acknowledges that processes function differently depending on the person and the context.

The role of the developing person in individual experiences. Results from previous studies have concluded that various person or individual characteristics, such as age at immigration, age, gender and family role will impact an individual's adjustment after migration (Berry & Sabatier, 2010; Ataca & Berry, 2002; Kwak & Berry, 2001; McDonald & Worswick, 2012; Kaplan, 1995). Recently, researchers have been acknowledging the significant role that having a member of the family diagnosed with a disability can play in the acculturation process (Accessibility for Ontarians with Disabilities Act, 2005; Cheikh, 2011; Ethno-Racial People with Disabilities Coalition of Ontario, 2003). By using narrative inquiry as the qualitative methodology in this study, the intricate differences in human experience as a result of these varying person characteristics became evident.

Support, access and perceived stressors depended on various factors such as the age of the participant and their children. In order to best determine how these factors intersected to create various fears or experiences of success, each woman's profile will be discussed below.

Simin. Simin was a young woman in her 30s with three children under the age of seven. From her perspective, she was not receiving sufficient early support and intervention to avoid putting her children in long-term difficulties, and as a result worried about their future. For example, Simin feared that without early support for her children's speech and language difficulties, they risked becoming shy and withdrawn adolescents. She viewed any financial or professional support that would be given to her family as an investment that would eventually help them get on their feet and contribute to the Canadian economy.

Banoo. Banoo was a woman in her 60s who had two children over the age of 30, both diagnosed with schizophrenia. Of all participants, Banoo and Fataneh were most vocal about the nature of their difficulties and their changing needs as they aged and their children matured. Banoo's daughter was diagnosed with schizophrenia in adulthood; at the time, her main concern was teaching her daughter independent living skills. Initially, the resources available in Canada were sufficient in helping Banoo meet her daughter's needs; she was hospitalized, found a group home, and eventually joined a working group in the hospital that taught her independent living skills. Even when the resources did not align with her needs due to cultural differences, the hospital staff worked with her to provide options that might suit her family's needs. It was not until Banoo's daughter had a child of her own that the nature of her needs changed. Her grandson was taken by Children's Aid Society in Toronto and was being raised in a foster home. Her concern for her daughter had now shifted toward the well-being of her grandson. On the other hand, her priority for her son, who was also diagnosed with schizophrenia as an adult, was to find a way to give him a sense of independence and autonomy in the same way that she had for her daughter. Banoo's concern, as she aged, was that her children would be cared for, and that they would be capable of living on their own when she passed away.

Dana. Between all participants, Dana and Banoo had the most number of similarities at all levels of Bronfenbrenner's systems theory (1979). In their microsystem, they were both living as single women raising their children in Toronto, ON. They had no family providing support, and they developed a support group with a number of other individuals where they would work to advocate for their children as a group. Their children had been diagnosed with schizophrenia, at the same age, and they described being stigmatized for this illness in very similar ways. With regards to their person demand characteristics, they were close in age and both were Iranian women. Like Banoo, Dana was concerned about her daughter's independence and autonomy. Her daughter was now in her 30s and Dana was her sole caregiver. As her daughter was non-verbal, Dana was looking for a culturally sensitive group home that would provide activities for her daughter in Farsi, but that would be sensitive to her needs and understand the various temporal factors, such as trauma experienced at the time of the Iran-Iraq war, on her daughter's development and diagnosis. Her main goal in finding this group home was to provide opportunities for her daughter to develop her independent living skills. Similar to Banoo's concerns for her son, Dana worried that her daughter would be left with no advocates when she passed away.

Fataneh. Fataneh was a woman in her 30s with a child in middle childhood, a period that spans 6-12 years of age and is a crucial time in children's social and emotional development (Huston & Ripke, 2006). Her son diagnosed with an Autism Spectrum Disorder, and in her narrative, her son's major concerns were about his self-image and fitting in with his peers. Changes children experience at this stage of development are centered on developing social and emotional worlds. Children at this age become much more aware of themselves in relation to their peers, and fitting in becomes takes on vital significance (Garcia & Marks, 2009). Her son appeared to be in the process of developing and questioning his own identity, and was rejecting his Iranian identity.

He was also experiencing puberty and questioning aspects of his sexual development. Given the nature of his disability, his mother worried about how his curiosity and questioning might manifest itself in public. She was concerned that he may ask questions, or touch someone out of innocent curiosity, and be ostracized or worse, criminalized by others. The nature of her concerns for his future then, had changed from her main concern centering on addressing his early academic needs in school, to issues of identity and sexual development.

Parvin. Parvin's individual characteristics were most similar to that of Fataneh. She was a woman in her 40s who, like Fataneh had a son in middle childhood. Her son was diagnosed with an Attention Deficit Hyperactivity Disorder, an invisible disability that was not a central component of her narrative. Her main concern for her son, like Fataneh, was his identity development, as he rejected Iran as his country of origin and searched for his own identity and friendships. The challenges faced by both Parvin and Fataneh's sons in the development of their identities are reflected in the literature. Potvin (2008) suggests that both first and second generation youth tend to feel identity conflict since, from the perspective of parental culture, they are rootless; but, from the standpoint of the host country's culture, they are still immigrants.

Ladan. Ladan had recently undergone a significant traumatic change in her life with the passing of her son. Prior to her son's death, she had been similar in many facets of her person characteristics to Banoo and Dana. As a woman in her 50s, she was concerned, although to a lesser degree, about facilitating her son's independence. Much of Ladan's narrative focused on the challenges that she had faced in the past, with the immigration system, with the stigma associated with disability, with service providers abusing her child, and with extended family's rejection of her son.

Other person characteristics, such as the disposition of the mother and child as well as their sense of self-efficacy in seeking service systems likely impacted the outcomes, however, these factors are not directly evident in any of the seven narratives.

The role of context in individual experiences. The experiences and proximal processes (Bronfenbrenner & Morris, 2006) described in the narrative varied substantially as a function of each individual's context. For example, within her microsystem, the environment immediately surrounding her, Fataneh had a supportive spouse and multiple siblings living in the city. In contrast, Ziba did not have a partner to support her efforts in accessing services for her child, and her immediate family was not in the country. As a result of the diagnosis of her child and due to the fact that her child was the result of an affair, she felt her opportunities to develop a social network of friends were limited. For Ziba, individuals within her exosystem, such as service providers became her closest level of support.

For the majority of the participants, their relationship with individuals and organizations in their exosystem depended on individual factors, and on their relationships with invidiuals in their microsystems. For example, the women's finances, the nature of their children's disabilities, and their level of spousal and family support impacted the types of services that they sought in supporting their children. Dana and Banoo are examples of two women who were similar in many aspects of their person, context and time factors. However, their experiences of interactions with service providers differed. Whereas the incidents recounted by Banoo were positive, Dana struggled with the way the system had criminalized her daughter, who was non-verbal and had difficulty expressing her needs. Her daughter had been given numerous labels and locked in a cell in the hospital without visitors. A narrative approach gave Dana the opportunity to verbalize the challenges she faced, and to discuss how her own dispositions, those of her child, and those of the service providers resulted in challenging interactions that impacted her experience.

The highest level of the systems, the macrosystem, includes the cultural context in which the women are living and developing. These women had all shared the same process of immigration from Iran to Canada, so the changes in the overall ideologies of both countries were similar across the narratives. There were however, some differences that came to light by using a narrative inquiry approach. Through my informal communication with the mothers who were curious to know about other participants, and to learn specifically about their children's diagnoses, it became evident that the level of stigma associated with schizophrenia and mental illness was significantly greater than an invisible disability such as Attention Deficit Hyperactivity Disorder. Additionally, participants had experienced their child's diagnosis at various points in time and in changing polital climates associated with various policies and ideologies. Time, the final factor impacting the mother's development in Canada will be discussed below.

Time. The final component of Bronfenbrenner's PPCT theory illustrates the importance of accounting for the multiple forms of temporality. Mesotime, the changing expectations of the larger society varied from beginning to the end of each woman's narratives and depended on the period during which each woman understood her child's disability. For example, Dana stressed that "schizophrenia didn't exist in Iran" at the time that her child first exhibited signs of the disorder, illustrating the way that both place and macrotime impacted her understanding of how to navigate support for her daughter. Similarly, Simin and Parvin both described the difference between their own worldviews and those of their parents or spouses. They attributed their own acceptance of mental health services to a change in the way that these services adapted on a large scale across time.

Addressing Themes and Sub-themes:

Individual narratives and Bronfenbrenner's PPCT theory (2006) illustrate the degree to which each woman's experience, regardless of the degree of similarity in their various person, context and time factors, was unique. Despite these differences, a number of overall themes sub-themes emerged as the most salient component of the participants' narratives. While acknowledging that there is no one unique experience of being an Iranian woman who has a child with a disability, these themes can serve as a useful source of information for community organizations in Toronto and researchers interested in better exploring the experiences of this population.

As the main goal of the study was to use narrative inquiry to explore the experiences of Iranian mothers who immigrated to Toronto, Ontario, Canada, procedural research questions were used to guide the mothers' narratives:

- What are the experiences of Iranian mothers who have a child with a disability in Iran?
- What stories can be told from the experiences during the immigration process to Toronto, ON?
- What are the experiences of Iranian mothers who have children with disabilities upon immigration to Toronto?

As evident in the first three questions, the original intention of the study was to better understand Iranian immigrant women's experiences of support in three milieus: in Iran, during the immigration process, and in Canada. However, six of the seven women interviewed had not had the experience of being the mother of a child with a diagnosis in Iran. The six women had either given birth to their children in Canada, or their children had been diagnosed in adulthood, post-immigration. As a result, the bulk of the study addressed the fourth and final guiding question and thus explored the experiences of mothers post-migration. A brief discussion of the first three questions in this section will speak to the case of Ladan, the only one of the seven women who had the experience of being the mother of a child with a disability in Iran, and later during the migration process to Toronto.

The case of Ladan: The experience of mothering a child who has a disability in Iran. In her narrative, Ladan described her experiences of emotional and professional support in Iran as lacking; her family rejected her child and visited her infrequently. In professional settings, her experience was no better as she discovered that her child had been tied to a chair and had experienced abuse at the hands of staff members in his day care centre. To a certain degree, Ladan's experiences were reflective of the realities of children with disabilities in Iran today. There have been advances in the opportunities for children with disabilities in Iran, mainly in the areas of education. The move toward Inclusive Education is a recent advancement for individuals with disabilities in Iran (The Iranian Special Education Organization, 2006; Samadi, 2008). Educational opportunities emerged in the 20th century with a number of non-governmental organizations and charities whose mandates were to provide an education to students with visual and hearing impairments, and to students with intellectual disabilities (Samadi, 2008; Kako-Joibari, 2003; The Iranian Special Education Organization, 2006). In 1968, the Iranian Ministry of Education took legal steps to acknowledge the educational needs of students with disabilities by establishing a dedicated education bureau (Samadi, 2008; Kako-Joibari, 2003). Shortly thereafter, immediately following the Iranian revolution (1979), The Iranian Special Education Organization (ISEO), an organization affiliated with the ministry of education, was established to address the needs of a growing population of individuals with disabilities (Kako-Joibari, 2003). Though policy infrastructure is in place in Iran, the abuse that Ladan's son suffered illustrates the degree to which changes in educational policies have not translated into effective and humane inclusive practices

(Kako-Joibari, 2003; Khayatzadeh, Rostami, Amirsalari, & Karimloo, 2013; Samadi, 2008). In addition to the social barriers experienced by Ladan's family, many families in Iran are faced with financial barriers that limit their access to support services for their children and that lead parents, predominantly mothers, to rely on support from their families (Kermanshahi et al., 2009; Khayatzadeh et al., 2013). In the case of Ladan, this social stigma extended to her family experiences, and she was consequently left with minimal social and emotional support.

The case of Ladan: The experience of immigrating with a child who has a disability. Of the seven women interviewed for the study, Ladan was alone in having had the experience of knowingly immigrating to Canada with a child who had been diagnosed with a disability. The lack of representation of immigrants with disabilities in this study may be due to the difficulty in recruiting participants as a result of the Immigration and Refugee Act excessive demand clause, which limits entry to to Canada when a member is diagnosed with a disability (Welcoming & Inclusive Communities Accessibility Project, 2011). A natural consequence of significant barriers to immigration is the reduced number of immigrants with disabilities living in Canada. According to the Welcoming and Inclusive Communities Accessibility Project (2011), despite the existence of the excessive demand clause, there are a significant number of newcomers with disabilities living in Canada, and other factors may limit their presence in research and practice. For example, newcomers with invisible disabilities may not have disclosed their disability prior to migration, or those with any number of visible or invisible disabilities may have been granted entry on humanitarian grounds. These participants may be reluctant to participate in research projects fearing that sharing their story will result in deportation, judgement or stigma. Ladan described the latter barrier to participation in her narrative when describing that her lawyer had warned her against accepting health cards for fear that her son would be deported, therefore such fears and mistrust would not be unfounded.

This fear of disclosure has important implications for practice, as immigrants with disabilities may not receive adequate supports. In addition, their perceived invisibility in Canada results in a lack of representation in research and policy (Welcoming and Inclusive Communities Accessibility Project, 2011). As a result, settlement workers are not adequately equipped to meet their needs. However, a recent acknowledgement of the relatively large number of newcomers with disabilities residing in Canada prompted a proliferation of qualitative research and recommendations for practice that address the needs of immigrants with disabilities in Canada (Accessibility for Ontarians with Disabilities Act, 2005; Cheikh, 2011; Ethno-Racial People with Disabilities Coalition of Ontario, 2003). The present study adds to this body of work by providing a qualitative account of experiences related to disability of a subset of immigrants, mothers from Iran. A discussion of the main themes that emerged from the narratives, situated within the current body of literature is addressed using the fourth and final sub-question: What are the experiences of mothers upon immigration to Toronto as they relate to accessing disability-related formal and informal supports and services for their children?

The experience of mothering as an immigrant Iranian woman whose child has a disability in Toronto, Ontario.

Although the first three sub-questions guiding the thesis were not applicable to six of the seven participants, the final sub-question, addressing the experiences of mothers in

Toronto, elicited seven rich narratives that were the basis for three broad themes. These themes were: interpreting and internalizing motherhood, managing systems of support, and success through education. A direct comparison of the results of this study with the literature is not possible, as the perspective of this population has never been voiced in research. However, the themes and sub-themes can be examined against literature that broadly examines motherhood, access to support for immigrants with disabilities, and the value of education in immigrant groups. The following sections will consist of a discussion of the each theme, beginning with the first major theme, interpreting and internalizing motherhood.

Interpreting and internalizing motherhood. The majority of the women had expressed experiencing rigid role responsibility and blame for their child's disability in their interaction with a variety of people in their immediate surroundings.

Role responsibility. The participant's family, service providers, and acquaintances attributed the children's disability to the mother's inability to adequately respond to their child's needs. Mothers experienced this role responsibility both by individuals within the Iranian community, but also by service providers and acquaintances in Canada. This theme is reflected in the literature on maternal responsibility in Western cultures as well as in ideologies and policy in Iran. In Canada and in the United States, mothers are idealized women who are selflessly available to their babies (Ambert, 1992; Caplan, 1989; Coll, Surrey, & Weingarten, 1998). This attribution of children's health to mothers has strong roots in history with mothers who were held responsible for the preservation and education (Badinter, 1981) and moral regulation (Arnup, 1994; Badinter, 1981; Ehrenreich & English, 2005; Ladd-Taylor & Umansky, 1998) of their children.

The ideal of the perfect mother has long been part of Iranian women's lives and is highlighted in the constitution of the Islamic Republic as a woman's main responsibility (Iran Chamber Society, 2014). However, despite efforts to convince women that their place is in the private realm attending to their families, women have prolonging marriage and family life in pursuit of employment and education (Rezai-Rashti & Moghadam, 2011). Researchers argue that there are a growing number of educated Iranian women who are challenging their second-class citizenship in the family and in Iranian society at large (Moghadam, 2003; Rezai-Rashti & Moghadam, 2011; Stromquist, 2006). This resistance was evident to some degree in the narratives of some participants, most significantly with Parvin who lived the duality of the expectation to fulfill the mother role, and the subsequent blame for the challenges that her son faced, and for the responsibility of being family's sole breadwinner. The other participants in the study also described this discrepancy between the expectations associated with motherhood and their lived experiences. Five of the seven women in the study had obtained undergraduate degrees in Iran, and two had received additional training to work in Canada. All of the women had worked at some point in time as either the only breadwinner (in three of the seven cases) or as a secondary breadwinner in the family. Two of the women stopped working due to high levels of stress and depression that they described resulting from their extreme helplessness and isolation in Canada. However, despite the high levels of employment in the families, the women all primarily described feelings of guilt when they fell short of fulfilling what they believed to be their roles and responsibilities as mothers. Studies support the idea that in Iran, mothers of children with disabilities often feel more guilt than other members of the family (Samadi, 2008; Sajedi, Alizad, Alaeddini, Fatemi, & Mazaherinezhad, 2008).

Blame. The participants described receiving messages of blame for failing to fulfill their maternal responsibility. These were predominantly from others within the Iranian community and from service providers. It should be noted that this could be due to a limited number of interactions with individuals from outside of the Iranian community.

The idea of women experiencing blame for challenges faced by their children is not direcltly addressed in the literature on Iranians with disabilities. However, anecdotal reports and general discourses within the community illustrate the degree to which these notions of mother blame are evident in Iranian women'wever, anecdot

The narratives in this study suggested that in addition to members of the Iranian community, service providers also engaged in mother blame. For example, Dana disclosed that nurses and doctors in the hospital had disregarded how a war in Iran might have impacted her daughter's behaviour and instead believed that Dana herself was a trigger for her daughter's negative behaviour. This theme of mother blame for immigrant families is evident in the literature. Mothers who have immigrated to North America have been found to face additional challenges as they are forced to adhere to white, middle-class standards of motherhood (Ladd-Taylor & Umansky, 1998). In the past, some immigrant women were labeled as "bad mothers" due cultural differences in child-rearing practices; service providers have engaged in disputes with mothers who swaddled their infants, fed them spicy foods, or attempted to ward off the evil eye instead of seeking medical support for their children (Ladd-Taylor, Umansky, 1998). This systemic blame has an inevitable influence on mothers who are facing challenges with acculturation and find themselves responsible for challenges faced by others within the family unit.

Maternal Protection. In addition to feelings of blame and maternal responsibility, participants reported feeling protective of their children in the face of discrimination or injustice. They illustrated feelings of protectiveness by advocating for their children against professional agencies that had caused them harm, as in the case of Dana who fought against the hospital system to protect her daughter and in the case of Ladan who protected her child from a respite agency that she believed had physically harmed him. They also protected their children against their own family members; Simin protected her children against the negative impact of their fathers' drugs and alcohol and Ladan distanced herself from her father who expressed disliking her child. Finally, Ziba protected her child against shame and stigma of community members who could potenitally associate his disability with punishment for his mothers' sins. Regardless of the context, all women were actively engaged in the protection of their children against harm. This theme was not directly addressed in the literature; studies addressed mothers' protection of their children mostly in cases of sexual or physical abuse. In fact, this protection is assumed to be part of maternal responsibility, and the absence of protection is the main subject of studies (Bolen, & Lamb, 2004; Coohey, & O'Leary, 2008; Sirles, & Franke, 1989). When women do not engage in the protection of their children, they are again pathologized and balmed for not fulfilling their responsibility as mothers.

Managing support networks. A second theme described by all women was their experiences of support, or lack-there-of, in financial, emotional, and service domains.

Support networks initiated by others. When service providers initiated support, it was most effective when introduced to women in a familiar domain. For example, the women's children had all at some point attended school in Toronto, a milieu that was essential and navigated by all families in this study, irrespective of their child's diagnosis. The women's interactions with their children's teachers often led to feedback on their child's development, and to support on how to access disability-related support when necessary.

Available accessible support. Although the women described negative aspects of their experience, they also specified their appreciation for the support in navigating the service-delivery system. Similarly, regardless of their child's disability, women found that their interactions with nurses and doctors before, during, and after the birth of their child to be supportive. For Simin, Ziba, this original interaction with nurses provided the necessary foundation for follow-up care. Once again, there were challenges and frustrations in this interaction that will be discussed in further detail below, however, the relationship provided professional support, and later extended to an avenue for financial support. Professionals in other typical settings, such as schools, were also a source of support for participants where they felt they could approach questions about difficulties faced by their children. There were few barriers in accessing these typical settings as schools and hospitals were familiar environments for the women and there was a reduced fear of stigmatization. Although parents in the study all noted that they reached out to their children's schools for support, success rates in accessing services varied across participants. This may partly be due to the face that educational policies addressing the needs of newcomers and students with disabilities vary greatly across provinces and even schools within jurisdictions in Canada. For example, there is variation in the allocation of resources for disability-related services and the criteria used to determine eligibility of services (Statistics Canada, 2004). In addition, the inconsistently of inclusion and diversity training in Ontario pre-service teacher training curricula is problematic. For schools to be effective avenues of support for all immigrant families with disabilities, pre-service teacher training would need to expand to include mandatory diversity, equity, and inclusion training (Peterborough Partnership Council on Immigrant Integration, 2012). An initiative known as the Settlement Workers in Schools Program (SWIS) has been developed to support a high number of newcomer students by placing settlement workers in schools. Despite the accessibility of this initiative, it was not mentioned by the participants in the study and did not appear to be a significant source of support for their children.

Typical settings are crucial avenues for support as immigrants with disabilities expressed that when first coming to Canada, they were unsure of which programs or services might best suit their needs, and settlement workers were poorly equipped to help. As a result, recommendations are made to provide settlement workers with a better understanding of how to support newcomers (Welcoming & Inclusive Communities Accessibility Project, 2011). Other organizations, such as the Ontario Council of Agencies Serving Immigrants (OCASI) and the Ethno-Racial People with Disabilities Coalition of Ontario (ERDCO) have been working to create more inclusive environments for newcomers with disabilities. For example the ERDCO created a Tip Tools Sheet for community organizations with information about disability-related access and cultural accommodations to assist with the development of programs, strategies, and outreach initiatives that are inclusive of ethnoracial people with disabilities (ERDCO, 2003).

These initiatives support the idea that inclusive community programs can be developed to better meet the needs of immigrants with disabilities and their families. Some researchers highlight that the most effective support network tend to be ones where members of the host society are included with immigrants (Garcia, 2002). This approach benefits psychological wellbeing by increasing perceived support from a wider social network (Birman, Trickett, & Vinokurov, 2002).

Inaccessible support. In line with findings from the Welcoming & Inclusive Communities (2011) initiative, individuals in this study were frustrated to know that their settlement workers or social workers were not equipped to provide them with information on how to access services and supports for their children. Many parents accessed services on their own, while as noted earlier, others tried to receive information and support from their childrens' schools.

The lack of sensitization of community programs, and the lack of training of settlement workers are not the only factors impacting immigrant Iranian women's experiences of professional support. Iranian families who have a child with a disability are most accustomed to relying on family support for their children as opposed to formal services (Kermanshahi, Vanaki, & Ahmadi, 2009). The availability of others who will help a new immigrant navigate the system and their child's disability may have an impact on the degree to which families will display service-seeking behaviours. However, many families do not have family support in Canada; according to the 2011 census data, approximately 25% of permanent residents were parents or grandparents and only approximately 2% fell under another category other than spouse or child (Citizenship and Immigration Canada, 2011). Furthermore, many disabilities continue to be a source of shame and stress for Iranian families (Samadi, 2008) and families may withhold support even from the closest friends and family due to disability.

Isolation: Pulled or pushed away. A significant portion of each narrative addressed participants' feelings of isolation. Often, the feelings of being pushed away by others or pulling away were intertwined and could not be clearly separated. Women who felt rejected by friends and family in the past were weary of new acquaintances and pulled themselves away from others to avoid future harm. In some instances, this isolation was not the result of direct rejection from others, but from societal views of mental illness. The degree to which the subject was taboo and unaccepted in their communities silenced them and forced their isolation.

The feelings of isolation noted by the participants are consistent with previous research findings examining the experiences of mothering children with disabilities in Iran and in Canada. Studies conducted in Iran suggest that families of children with disabilities are socially isolated by their communities and within their own families. The lack of family and community support is exacerbated for mothers who feel solely responsible for the burden of care (Kermanshahi et al., 2008; Kermanshahi et al., 2009; Khodabakhshi Koolaee & Etemadi, 2010).

In North America, despite self and parent advocacy efforts, mothers face stigma as a result of their child's disability (Green, 2002, 2003), which can lead to experiences of increased emotional distress and social isolation (Blum, 1991; MacRae, 1999). As a response to the stigma that families experience, they may reduce their interactions with others by pulling away from their community and by interacting mainly with others who are familiar with the experience of disability (Birenbaum, 1992; Green, 2001, Green, Davis, Karshmer, Marsh, & Straight, 2005; Ringsberg, Lepp, & Finnstrom, 2002). In Canada, studies of various immigrant groups whose children have been diagnosed with a disability have found that family, peer and community support were instrumental in helping through experiences of suffering (Cheikh, 2011; Daudji et al., 2011).

Support networks initiated by self. During times the support was unavailable to the participants, they took initiative and found ways of creating accessible systems of support for themselves and for others around them.

Initiating support for self and others. Participants initiated support by forming support groups, by changing their field of eduction to inform themselves about how to best support their child, and by sharing their stories in hopes of supporting women in similar circumstances.

Due to a lack of family support, parents describe feeling a sense of belonging and support by meeting with other parents of children with disabilities (Cheikh, 2011; Chien, Norman & Thompson, 2006; Daudji et al., 2011; Ruffolo, Kuhn & Evans, 2010;). Creating these support groups and attenting to them with other families who have similar experiences with disability have been found to reduce the self-blame experienced by mothers in some populations (Maloni et al., 2010).

In addition to the creation of social support networks, mothers have been actively finding ways of educating themselves about how to best support their children, both formally and informally and of sharing this knowledge with others. A great number of researchers in the field of education have been writing from the dual perspective of a mother of a child with a disability and of a researcher to better inform others of the experience of the intersecting identities of motherhood and disability (Carr, 1993; Green, 2001, 2002, 2003) and to provide insight into how to best support these children in various contexts (Carr, 1993; Turnbull, Turnbull, Erwin, Soodak, & Shogren 2011).

The women who participated in the study sought to use their voices in a way to support others much similar to Carr (1993) and Green (2002), but were limited due to a number of barriers they faced in this process.

Barriers in creating support. Mothers were faced with significant roadblocks in initiating their own systems of support. These barriers included challenges in access to material that would allow the women to open their own group homes organizations of support for Iranians with disabilities. In addition, parents were faced with barriers in advocating for their children's rights in the school setting. The readability of parents' rights handbooks exceeds the reading skills of many parents, creating a potential barrier for some parents in their advocacy (Fitzgerald & Watkins, 2006). Language barriers can add an extra layer of difficulty in parent participation in advocacy (Lian & Fontánez-Phelan, 2001). Parents whose first language is not English are therefore required to have materials in their first language in order to effectively participate in efforts to create systems of support for their children (Trainor, 2010).

Success through education. The participants all noted the importance of education by highlighting the belief that knowledge can empower them and their children. They pursued this knowledge in informal domains, such as through workshops or support groups, to understand their child's exceptionality. They also formally sought degrees to better understand how to best meet the needs of their children. Additionally, they viewed their children's positive educational experiences as a sign of success; Ladan and Fatemeh both changed professions to spend more time in their child's school and support their education, while Banoo and Dana both described their children's high academic achievement as indicators of successful and healthy children. Banoo hoped that her son's continued thirst for knowledge might serve as a protective factor in his emotional adjustment. Finally, Parvin and Simin both worried about the impact of stressors on their children's long-term educational achievement; as noted earlier, Parvin stressed the value of education disconnected from vocational success by stating that she hoped that her daughter would get a PhD, regardless of the vocation she chose.

The high value placed on education is not unique to the women in this study, or to Iranian immigrants. The *Youth in Transition Survey* (2004) conducted by Statistics Canada found that the majority of immigrant youth have very high educational aspirations and there is evidence suggesting that these high aspirations are a result of the high value placed on education by immigrant families (Ghuman, 1980; Ghuman & Wong, 1989; Gibson, 1987; Hayes, 1992). One study of Central American Hispanic immigrants in the United States found that "education was regarded as the most significant avenue to status mobility in the new land" (Suarez-Orosco, 1991, p.46).

Canada's immigration policy encourages migration of families who place high value on education, as the policy has focused on recruiting educated, skilled immigrants to satisfy its labor market needs (Statistics Canada, 2013). The high value placed on education and aspirations are not exclusive to immigrant Iranian children, as an increasing number of Iranian women enrolling in higher education programs (Rezai-Rashti & Moghadam, 2011) suggest that the women place high value on their own educational attainment as well. In Canada, high levels of education have not translated to increased employment opportunities for immigrants (Reitz, 2007; Picot, 2004). As a result, Iranian women are finding ways of improving their own credentials or making use of educational opportunities more frequently than their male counterparts (Dilmaghani, 1999). This was reflected in the way women in the study, namely Parvin, Dana and Fataneh upgraded their credentials to increase their knowledge of how to support their child. After the completion of the study, Simin shared that she too had upgraded her credentials and found an employment opportunity close to her home.

Strengths and Limitations of the Current Study

This study was intended to make a contribution to the fields of immigration and disability by examining the experience of immigrant Iranian women who had a child with a disability from their own perspective. From it, numerous ideas emerge about types of support experienced by the women, their isolation, as well as their expectations related to motherhood and their experiences of blame. The discussion highlighted the diversity of women's experiences and used a developmental systems approach to understand the ways that individual, temporal and contextual factors impacted experiences of adjustment and support post-migration. In this section, I begin by providing a summary of the strengths my study followed by some of the limitations. I will then address proposals and recommendations that could serve to bridge the divide between theory and practice. Finally, the chapter will come to a close with my reflections on my own personal characteristics and their contribution to the research project.

Strengths and original contributions. The strengths of this study include its contribution to the literature, the use of a constructivist lens to give voice to Iranian mothers who have a child with a disability, a marginalized population, through a qualitative transparent design, with a focus on credibility or trustworthiness. Coming from the perspective of an Iranian woman who spoke the language and understood the culture of participants, I was able to speak to individuals who would have barriers in communication with professionals and other individuals from the host community. Further, the connection my family had to the Iranian community in Toronto made a significant difference in recruitment efforts, as was illustrated by my five months of failed recruitment attempts in Montreal, QC.

Recent research efforts have acknowledged the importance of providing appropriate services for newcomers with disabilities following immigration to Ontario. Given the complexity of the factors that impact the immigration process, the perception of parents in accessing services for their children, especially mothers, who continue to be held responsible for their children's healthy development was not adequately examined. This study adds to the growing body of literature examining parents perspectives and considers how culture and country of origin might impact experiences of support in Ontario. Finally, given the use of narrative inquiry as methodology, a rich description of experiences is provided as a story from the point of migration all within a developmental framework. These accounts can be used as a starting point for further research and participatory action projects. By combining the contextualized narratives with categorization for analysis, an overall picture of these women's experiences emerged that provides insight into how to adapt community supports to their needs.

Limitations. The greatest limitation in this study was the significant challenge in recruiting participants. Recruitment efforts in Montreal were unsuccessful, but spanned approximately a five-month period. The recruitment was then taken to Toronto, Ontario where another five months were spent recruiting and interviewing participants.

Participants noted that the sensitive nature of the narratives and the fear of being identified through in-depth narratives had made them hesitant and had deterred their acquaintances from participating in the study. Others, most notably Ladan, had lost trust in the system and didn't believe that participating in the study would bring positive change, and so participated reluctantly. This limitation highlights the stigma experienced by these families, and their mistrust of organisms of supports. Thus, the participants are perhaps not an adequate representation of Iranian mothers of children with disabilities living in Toronto.

A second limitation relates to the first, and is related to the diversity of experiences of the participants whose children's diagnoses spanned mental illness to physical disabilities, to invisible disabilities such as anxiety disorders. There is a clear difference between the services and supports available to each individual depending on various person characteristics of the mothers and her children. Due to the difficulty accessing participants, these differences could not be understood as they might relate to each one of the intersecting person characteristics. For example, if all children had been diagnosed with an Autism Spectrum Disorder, developmental differences between participants may be more evident. Additionally, potential gaps and needs in services and supports could be identified that may better consider the specific needs of certain populations. However, due to the study's first limitation of difficulty with recruitment, it was unrealistic to further reduce the number of possible participants by narrowing the criteria.

The exclusion of Iranian fathers' experiences accessing supports and services for their children who have disabilities is a limitation of this study. Given the changing face of the family in the 21st century, many families, including those who participated in this study are no longer nuclear, and when they are, mothers are not the sole caregivers. However, as noted in the literature review, studies of Iranian immigrants have found that men and women express differences in their experiences of challenges post-migration, and they have been found to rely on different coping mechanisms for support. Additionally, despite changes in North American family structures, many Iranian families have maintained traditional gender roles with women occupying most of the responsibility in the private sphere. It was therefore important to understand the experiences of mothers. However, men also have experiences of adjustment and acculturation associated with their child's disability, and their perspectives should be considered in future studies.

In addition, there are various cultural and linguistic groups living in Iran, including individuals who speak Balouchi, Kurdish, Lori, Azari, and Gilaki as their mother tongue. If participants who identified as Iranian spoke one of the aforementioned language but not Farsi, French or English, their voices were not included in this study.

Implications and recommendations for practice. The women who participated in this research study did so hoping that the findings would be disseminated and ideally transformed into practical change. The areas of need described by the participants can be divided into three categories: reducing isolation through the development of supportive social networks, increasing access to support by providing essential information through typical professional settings, and providing opportunities for education, empowerment, and self-determined advancement.

The first of these categories, reducing isolation can be achieved in a number of ways. The first is through the creation of support groups for Iranian families whose children have diagnoses. According to the literature, family, relatives and the ethnic community provide the most critical social support to new immigrants (Finch & Vega, 2003; Garcia et al., 2002; Jasinskaja-Lahti & Liebkind, 2001; Noh & Kaspar, 2003; Vega et al., 1991). As noted in this study, when a member of the family has been diagnosed with a disability, some of these social support structures may break down or become unavailable. In such cases, individuals with the same ethnic background and disability-type have been found to act as sources of social support (Cheikh, 2011). This finding was supported by a couple of narratives in this study, where mothers of now-adults with schizophrenia described meeting regularly and advocating on behalf of all their children. Not only did the women describe the meetings as a source of emotional support, but they also served as a means of obtaining professional support for the group.

One challenge with creating networks of support for Iranian families who have a child with a disability is overcoming the difficulties that can act as the source of isolation, such as the shame and stigma described by the women in the study. Even without the added stigma of disability, the establishment of interpersonal support network can be difficult for immigrant groups (Garcia, Ramirez, & Jariego, 2002), but adding layers of mistrust and blame, families may be reluctant to form networks, even if they know they exist. Many families in this study described making use of the telephone and online tools to maintain communication with their trusted family and friends in Iran but had not yet established similar networks in Canada. One potential source of relatively anonymous support might be the use of online networks as a means to connect Iranian families in Canada. By connecting with others through online communities, the need to disclose their identity is reduced and the possibility of connecting to others with similar experiences is increased. A second means of creating support networks could spark from a participatory research project involving the mothers who participated in this study and had children who were diagnosed with schizophrenia. Those women, along with other parents had found ways of breaking down barriers and initiating a support group. Their feedback could be extremely valuable in understanding how to overcome barriers in accessing face-to-face support groups.

The second recommendation to inform professionals in typical settings, such as teachers and social workers in schools and nurses in hospitals of the ways in which they can support immigrant families to better access supports and services. The challenge here is that nurses and teachers are often overwhelmed and overburdened with the responsibility within their current roles, and may have limited time and resources to adequately support a family in navigating care, no matter how well-intentioned. It could therefore be useful to create a series of pamphlets, brochures and information in a variety of languages, including Farsi, and make them available within these professional settings. Similar pamphlets and websites are currently available to immigrant families in Toronto without addressing access to disability-specific services (“Immigration Portal”, n.d.; “Local Immigration Partnership”, 2014; “Newcomers Toronto Fair”, 2014; Toronto Immigrant Services, 2014). Working together with professionals in disability-specific centres to create pamphlets that are available in a variety of languages will ensure up-to-date information is provided to new immigrants. It also ensures that language or cultural barriers will not stand in the way of communicating the information to the parents. In addition, the nurse or teacher is not responsible to find the time to research and learn about the various services relating to different disabilities.

Finally, the last recommendation relates to creating educational opportunities for parents to learn about their children's exceptionalities, the health and education systems in Toronto, ON and support in managing their relationships with their spouses and children. In addition, some mothers expressed the need to learn about how to effectively initiate their own group homes and centres for children with disabilities. In order to create immediate small change while waiting to learn about the time-consuming process of creating a group home, a number of mothers discussed beginning with a small venture, such as a weekly art class or movie for adults with schizophrenia in an Iranian community centre. Such ventures may eventually help reduce isolation and stigma and increase the presence of individuals with disabilities within the Iranian community.

Implications for further research. Based on the results of this study, the most pressing need for further research is the use of a participatory action research project to create support services for Iranian families of children with disabilities. Participatory action research (PAR) is based on reflection, data collection, and action by involving the people who take actions to improve their own health and reduce health inequities (Baum, MacDougall & Smith, 2006). The presence of a current support group of parents who have children diagnosed with schizophrenia, who are motivated and determined to create support within the community and advocate on behalf of their children makes the need for such research necessary.

Other studies would equally contribute to the literature and enrich the findings of this study. For example, the experiences of Iranian fathers and siblings of children who have a disability, as well as the experience of the children themselves can be useful in gaining a more thorough understanding of the needs of this community as a whole. In addition, the perspective of health care providers and education professionals could help understand how to best make use of typical professional settings to address the needs of immigrant Iranian families. Finally, examining immigrants as a group, without isolating Iranian families is equally important, as there are challenges associated with immigration and disability across all countries of origin. Finally, the usefulness of online communication tools as a means of reducing isolation among immigrant families who have a child with a disability should be examined.

Concluding Comments

Immigrant Iranian mothers' experiences of caring for their children who have a disability are complex and depend on various individual, contextual and temporal factors. Overall, these factors led mothers to interpret their roles and responsibilities as mothers and internalize messages of mother blame. In addition, various levels of accessible and inaccessible support were available with typical settings such as schools and hospitals acting as the most significant locales of support. When support was unavailable, Iranian mothers initiated ways of accessing services both for themselves and for others. Often, education was used as the tool that empowered the women and their children and provided avenues for support.

There needs to be more awareness of the internalized messages of responsibility and blame experienced by mothers. Community members, researchers and practitioners should be cognizant of their role in perpetuating these messages. Schools and hospitals as well as other typical settings should be better equipped to provide newcomers with disabilities with access to supports and services. As part of this support, pamphlets, websites and informational sites should be linguistically accommodating by providing information in accessible language. In addition, future research and practice initiatives should consider ways of empowering mothers through participatory action.

REFERENCES

Adibsereshki, N., & Salehpour, Y. (2012). Peer acceptance of students with and without inclusion experience towards students with special needs in unisex schools of Tehran. *Education 3-13*(3), 1-14.

Adibsereshki, N., Tajrishi, M. P., & Mirzamani, M. (2010). The effectiveness of a preparatory students programme on promoting peer acceptance of students with physical disabilities in inclusive schools of Tehran. *Educational Studies, 36*(4), 447-459.

Ahmed, A. (2008). *Iranians in Canada by the numbers.* Retrieved from http://www.payvand.com/news/08/jun/1202.html

Alba, R. D., & Nee, V. (2003). *Remaking the American mainstream assimilation and contemporary immigration.* Cambridge, MA: Harvard University Press.

Albanese, P. A. (2009) *Children in Canada Today*. Don Mills, ON: Oxford.

Albanese, P.A. (2005). Ethnic Families, in M. Baker (Ed.), *Families: Changing Trends in Canada, 5th Edition*. (pp. 121-142). Toronto: McGraw-Hill Ryerson.

Alboim, N., & Cohl, K. (2012). *Shaping the future: Canada's rapidly changing immigration policies.* Retrieved from: http://maytree.com/wp-content/uploads/2012/10/shaping-the-future.pdf.

Allen, J.A. (1994) The constructivist paradigm, *Journal of Teaching in Social Work*, *8*, 31-54**.**

Ambert, A.M. (1992). *The effect of children on parents*. New York: Haworth Press.

Arnup, K. (1994). *Education for motherhood: Advice for mothers in twentieth-century Canada*. Toronto; Buffalo: University of Toronto Press.

Ataca, B., & Berry, J. W. (2002). Psychological, sociocultural, and marital adaptation of Turkish immigrant couples in Canada. *International Journal of Psychology*, *37*(1), 13-26.

Aydemir, A., & Skuterud, M. (2008). The immigrant wage differential within and across establishments. *Industrial & Labor Relations Review, 61*(3), 33

Badinter, E. (1981). *Mother love: Myth and reality: Motherhood in modern history*. New York: Macmillan.

Bagheri, A. (1992). Psychiatric problems among Iranian immigrants in Canada. *Canadian Journal of Psychiatry, 37*(1), 7-11.

Bernhard, J.K., Freire, M., Pacini-Ketchabaw, V., & Villanueva, V. (1998). A Latin-American parents' group participates in their children's schooling: Parent involvement reconsidered. *Canadian Ethnic Studies, 30,* 77-98.

Bernhard, J., & Freire, M. (1999). What is my child learning at elementary school? Culturally contested issues between teachers and Latin American families. *Canadian Ethnic Studies, 31*(3), 72-94.

Berry, J. W. (1997). Immigration, acculturation and adaptation. *Applied Psychology: An International Review, 46,* 5-34.

Berry, J. W. (2001). A psychology of immigration. *Journal of Social Issues, 57*, 615-631.

Berry, J. W., & Sabatier, C. (2010). Acculturation, discrimination, and adaptation among second generation immigrant youth in Montreal and Paris. *International Journal of Intercultural Relations, 34*(3), 191-207.

Bhugra, D. (2004). Migration, distress and cultural identity. *British Medical Bulletin, 69,* 129-141.

Biles, J., Tolley, E., & Ibrahim, H. (2005). Does Canada have a multicultural future? *Canadian Diversity Canadienne, 4*, 23-28.

Birenbaum, A. (1992) Courtesy stigma revisited, *Mental Retardation*, *30*, 265-268.

Birman, D., Trickett, E. J., & Vinokurov, A. (2002). Acculturation and adaptation of Soviet Jewish refugee adolescents: Predictors of adjustment across life domains. *American Journal of Community Psychology, 30*(5), 585-607.

Blum, N.S. (1991). The management of stigma by Alzheimer family caregivers, *Journal of Contemporary Ethnography, 20*, 263–84.

Bolen, R. M., & Lamb, J. L. (2004). Ambivalence of nonoffending guardians after child sexual abuse disclosure. *Journal of Interpersonal Violence, 19*(2), 185-211.

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

Bronfenbrenner, U. (1986). Ecology of the family as a context for human development: Research perspectives. *Developmental Psychology, 22,* 723-742.

Bronfenbrenner, U., & Morris, P. A. (2006). The bioecological model of human development. In W. Damon & R. M. Lerner (Eds.), *Handbook of child psychology, Volume 1: Theoretical models of human development* (pp. 793-828). New York: Wiley.

Bruner, J. S. (1990). *Acts of meaning*. Cambridge, Mass.: Harvard University Press.

Bucholtz, M. (2007). Variation in transcription. *Discourse Studies, 9*(6), 784-808.

Burr, K. (2011). *Local immigration partnerships: Building welcome and inclusive communities through multi-level governance*. Retrieved from:

http://p2pcanada.ca/files/2011/10/Local-Immigration-Partnerships-Building-Welcoming-and-Inclusive-Communities.pdf

Butler-Kisber, L. (2010). *Qualitative inquiry: Thematic, narrative and arts-informed perspectives*. Los Angeles; London: SAGE.

Caplan, P. J. (1989). *Don't blame mother: Mending the mother-daughter relationship*. New York: Harper & Row.

Carr, M. (1993). A mother's thoughts on inclusion. *Journal of Learning Disabilities, 26*(9), 590-592.

Chadha, E., (2008). "Mentally defectives" not welcome: Mental disability in Canadian immigration law. *Disability Studies Quarterly,* 28(1). LOOK UP PAGES

Cheikh, I. B. (2011). *Autisme chez des enfants d'immigration récente: l'expérience de familles originaires du Maghreb.* [Powerpoint slides] retrieved from http://www.csssdelamontagne.qc.ca/fileadmin/csss_dlm/Activites_de_recherche/DIAPO_2011_10_20.pdf

Chien, W.T., Norman, I., & Thompson, D. (2006). Perceived benefits and difficulties experienced in a mutual support group for family carers of people with Schizophrenia. *Qualitative Health Research, 16*(7), 962-981.

Citizenship and Immigration Canada. (2005). *Recent immigrants in metropolitan areas: A comparative profile based on the 2001 census.* Retrieved from www.cic.gc.ca/english/resources/research/census2001/canada/parta.asp.

Citizenship and Immigration Canada. (2010). *Immigrating to Canada.* Retrieved from http://www.cic.gc.ca/english/immigrate/index.asp.

Citizenship and Immigration Canada. (2011). *Permanent and temporary residents.* Retrieved from http://www.cic.gc.ca/english/resources/statistics/menu-fact.asp.

Clandinin, D. J. (2013). *Engaging in Narrative Inquiry*. Walnut Creek, CA: Left Coast Press.

Clandinin, D. J., & Connelly, F. M. (2000). *Narrative inquiry: Experience and story in qualitative research*. San Francisco: Jossey-Bass Publishers.

Clandinin, D.J., & Huber, J. (2010). Narrative inquiry. In B. McGraw, E. Baker, & P. P. Peterson (Eds.), *International encyclopedia of education* (3rd ed.). New York, NY : Elsevier

Cohen, E. H. (2011). Impact of the group of co-migrants on strategies of acculturation: Towards an expansion of the Berry model. *International Migration, 49*(4), 1-22.

Coll, C. T. G., Surrey, J. L., & Weingarten, K. (1998). *Mothering against the odds: Diverse voices of contemporary mothers*. New York: Guilford Press.

Connelly, F. M., & Clandinin, D. J., (2006). Narrative inquiry. In J. Green, G. Camilli, & P. Elmore (Eds.), *Handbook of complementary methods in education research*. (pp. 375-385). Mahwah, NJ: Lawrence Erlbaum.

Coohey, C., & OLeary, P. (2008). Mothers protection of their children after discovering they have been sexually abused: An information-processing perspective. *Child Abuse Neglect, 32*(2), 245-259.

Council of Canadians with Disabilities. (n.d.). *Immigration and People with Disabilities.* Retrieved from http://www.ccdonline.ca/en/socialpolicy/immigration

Council of Canadians with Disabilities. (2011*). CCD Dismayed Family with Disabled Child Ordered Deported.* Retrieved from http://www.ccdonline.ca/en/socialpolicy/access-inclusion/press-release-immigration-13april2011.

Creswell, J. W. (2007). Qualitative inquiry and research design: Choosing among five Approaches. Thousand Oaks, CA: Sage.

Cutcliffe, J. (1997). Qualitative research in nursing: A quest for quality. *British Journal of Nursing, 6*(17).

Dabrowska, A., & Pisula, E. (2010). Parenting stress and coping styles in mothers and fathers of pre-school children with autism and Down syndrome. *Journal of Intellectual Disability Research, 54*(3), 266-280.

Dastjerdi, M. (2007). Becoming self-sufficient : the experience of Iranian immigrants who access Canadian health care services. *Dissertation Abstracts University of Alberta.*

Dastjerdi, M. (2012). The case of Iranian immigrants in the greater Toronto area: A qualitative study. *International Journal for Equity in Health, 11*(1).

Dastjerdi, M., Olson, K., & Ogilvie, L. (2012). A study of Iranian immigrants' experiences of accessing Canadian health care services: A grounded theory. *International journal for equity in health, 11*.

Daudji, A., Eby, S., Foo, T., Ladak, F., Sinclair, C., Landry, M. D., Gibson, B. E. (2011). Perceptions of disability among south Asian immigrant mothers of children with disabilities in Canada: Implications for rehabilitation service delivery. *Disability and Rehabilitation, 33*(6), 511-521.

Davis, N., & Carter, A. (2008). Parenting stress in mothers and fathers of toddlers with Autism Spectrum Disorders: Associations with child characteristics. *Journal of Autism and Developmental Disorders, 38*(7), 1278-1291.

DiCicco-Bloom, B., & Crabtree, B. F. (2006). The qualitative research interview. *Medical Education, 40*(4), 314-321.

Dilmaghani, S. (1999). *Who are we? The Iranians in Toronto today: Profile, contributions and issues.* Retrieved from: http://ceris.metropolis.net/Virtual%20Library/community/dilmaghani1/dilmaghani1.pdf

Donmoyer, R. (1990). Generalizability and the single case study. In E. Eisner and A. Peshkin (Eds.), *Qualitative research in education: The continuing debate* (pp. 175–200). New York: Teachers College Press.

Dyson, L. L. (2001). Home-school communication and expectations of recent Chinese immigrants. *Canadian Journal of Education, 26*, 455-476.

Egbo, B. (2009). *Teaching for diversity in Canadian schools.* Toronto: Pearson.

Ehrenreich, B., & Deidre, E. (2005). *For her own good: Two centuries of the experts' advice to women*. New York: Anchor Books.

Eisner, E. W. (1991). *The enlightened eye: Qualitative inquiry and the enhancement of educational practice*. New York, NY: Macmillan Publication Company.

El-Lahib, Y., & Wehbi, S. (2012). Immigration and disability: Ableism in the policies of the Canadian state. *International Social Work, 55*, 95-108.

Emami, A., Benner, P., & Ekman, S. L. (2001). A sociocultural health model for late-in-life immigrants. *Journal of Transcultural Nursing, 12*(1), 15-24.

Employment and Social Development, Canada (2013). *Canadians in Context - Immigration.* Retrieved from http://www4.hrsdc.gc.ca/.3ndic.1t.4r@-eng.jsp?iid=38.

Eunjung, K. (2002). The relationship between parental involvement and children's educational achievement in the Korean American family. *Dissertations Abstracts International, 62*, 3201A.

Ferrer, A. M., & Riddell, W. C. (2002). The role of credentials in the Canadian labour market. *Canadian Journal of Economics, 35*(4), 879-905.

Ferrer, A.M., & Riddell, W.C. (2008). Education, credentials and immigrant earnings *Canadian Journal of Economics; 41*(1), 86-216.

Fischer, C. T. (1984). A phenomenological study of being criminally victimized: Contributions and constraints of qualitative research. *Journal of Social Issues, 40*(1), 161-177.

Frenette, M., & Morissette, R. (2005). Will they ever converge? Earnings of immigrant and Canadian-born workers over the last two decades. *International Migration Review, 39*(1), 228-257.

Galarneau, D., & Morissette, R. (2008). *Immigrants' education and required job skills.* Retrieved from: http://www.statcan.gc.ca/pub/75-001-x/2008112/pdf/10766-eng.pdf.

GarcÌa, A. M. (2002). *The Mexican Americans*. Westport, Conneticut: Greenwood Press.

Garcia, C., C., & Marks, A., K. (2009). *Immigrant stories ethnicity and academics in middle childhood*. New York: Oxford University Press.

Garousi, V. (2005). *Iranians in Canada: A statistical analysis.* Retrieved from:

http://iranian.com/News/2005/June/IraniansCanada.pdf.

Gergen, M. (2001). *Feminist reconstructions in psychology: Narrative, gender & performance.* Thousand Oaks, CA; London: Sage.

Gergen, K. J., & Gergen, M. M. (2010). Scanning the landscape of narrative inquiry. *Social and Personality Psychology Compass, 4*(9), 728-735.

Ghuman, P. (1980). Punjabi parents and English education. *Education Research, 22*(1), 121-130.

Ghuman, P., & Wong, R. (1989). Chinese parents and English education. *Education Research, 31*(2), 134-131.

Gibson, M. (1987). The school performance of immigrant minorities: A comparative view. *Anthropology and Education Quarterly, 18*, 262-267.

Green, S. E. (2001). Oh, those therapists will become your best friends: Maternal satisfaction with clinics providing physical, occupational and speech therapy services to children with disabilities. *Sociology of Health and Illness, 23*, 798-828.

Green, S.E. (2002). Mothering Amanda: Musings on the experience of raising a child with Cerebral Palsy. *Journal of Loss and Trauma, 7*(1), 21-34.

Green, S. E. (2003). "What do you mean what's wrong with her?'": Stigma and the lives of families of children with disabilities. *Social Science & Medicine, 57*(8), 1361-1374.

Green, S., Davis, C., Karshmer, E., Marsh, P., & Straight, B. (2005). Living Stigma: The impact of labeling, stereotyping, separation, status loss, and discrimination in the lives of individuals with disabilities and their families. *Sociological Inquiry, 75*(2), 197-215.

Green, D. A., & Worswick, C. (2012). Immigrant earnings profiles in the presence of human capital investment: Measuring cohort and macro effects. *Labour Economics, 19*(2), 241-259.

Groce, N. E. (2006). Inside deaf culture. *American Anthropologist, 108*(2), 430-431.

Guba, E. G., & Lincoln, Y. S. (1994). Competing paradigms in qualitative research. In N. K. Denzin & Y.S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 105-117). Thousand Oaks, CA: Sage.

Habermas, J. (1990). *Moral Consciousness and Communicative Action,* Cambridge, Massachusetts: MIT Press.

Hakimzadeh, S. (2006). Iran: A vast diaspora abroad and millions of refugees at home. *Online Journal of the Migration Policy Institute*. Retrieved from http://www.migrationpolicy.org/article/iran-vast-diaspora-abroad-and-millions-refugees-home.

Haque, E. (2005). *Multiculturalism within a bilingual framework: Language and the racial ordering of difference and belonging in Canada.* Toronto: University of Toronto Press.

Hawkins, F. (1988). *Canada and immigration: Public policy and public concern*. Kingston: Institute of Public Administration of Canada; McGill-Queen's University Press.

Hayes, K. (1992). Attitudes towards education: Voluntary and involuntary immigrants from the same families. *Anthropology and Education Quarterly, 23*(3), 250-267.

Huston, A. C., & Ripke, M. N. (2006). *Developmental contexts in middle childhood: Bridges to adolescence and adulthood*. Cambridge, UK; New York: Cambridge University Press.

Hunter, C., Nixon, J., & Parr, S. (2010). Mother abuse: A matter of youth justice, child welfare or domestic violence? *Journal of Law and Society, 37*(2), 264-284.

Hyman, I. (2004). Setting the stage: Reviewing current knowledge on the health of Canadian immigrants. What is the evidence and where are the gaps*? Canadian Journal of Public Health, 95*, 1–4.

Immigration and Refugee Protection Act, SC 2001, c 27, (http://canlii.ca/t/526n1).

Iran Chamber Society. (2014). *The constitution of Islamic Republic of Iran.* Retrieved from: http://www.iranchamber.com/government/laws/constitution.php

Isajiw, W. W. (1999). *Understanding diversity: Ethnicity and race in the Canadian context*. Toronto: Thompson Educational Publications.

Jackson, D., Mannix, J. (2004). Giving voice to the burden of blame: A feminist study of mothers' experiences of mother blaming. *International Journal of Nursing Practice,* 150-158

Johnson, B., & Christensen, L. B. (2000). *Educational research: Quantitative and qualitative approaches*. Boston: Allyn and Bacon.

Joyal, R, Government of Canada (1994). *The Canada-Quebec accord made easy.* Retrieved from: http://www.cic.gc.ca/english/DEPARTMENT/LAWS-POLICY/agreements/quebec/can-que-guide.asp

Kauffman, E., Perry, A., & Prentiss, D. (2001). Reasons for and solutions to lack of parent involvement of parents of second language learners. *ERIC Document*, 458-956

Kako Joibari, A. A. (2003). *Perspectives on inclusive education in the Islamic Republic of Iran, Enabling Education Network*. Retrieved from: http://www.eenet.org.uk/resources/docs/iran.php

Kelley, N., & Trebilcock, M. J. (1998). *The making of the mosaic a history of Canadian immigration policy*. Toronto: University of Toronto Press.

Kermanshahi, S. M. K., Vanaki, Z., Ahmadi, F., & Azadfalah, P. (2009). Perceived support among Iranian mothers of children with learning disability. *Rehabilitation Nursing, 34*(4), 135-140.

Kermanshahi, S. M., Vanaki, Z., Ahmadi, F., Kazemnejad, A., Mordoch, E., & Azadfalah, P. (2008). Iranian mothers' perceptions of their lives with children with mental retardation: A preliminary phenomenological investigation. *Journal of Developmental and Physical Disabilities, 20*(4), 317-326.

Khayatzadeh, M., Rostami, H. R., Amirsalari, S., & Karimloo, M. (2013). Investigation of quality of life in mothers of children with cerebral palsy in Iran: Association with socio-economic status, marital satisfaction and fatigue. *Disability and Rehabilitation, 35*(10), 803-808.

Khodabakhshi Koolaee, A., & Etemadi, A. (2010). The outcome of family interventions for the mothers of schizophrenia patients in Iran. *International Journal of Social Psychiatry, 56*(6), 634-646.

Kim, E. (2011). Intergenerational acculturation conflict and Korean American parents' depression symptoms. *Issues in Mental Health Nursing, 32*(11), 687-695.

Kwak, K., & Berry, J. (2001). Generational differences in acculturation among Asian families in Canada: A comparison of Vietnamese, Korean, and East-Indian groups. *International Journal of Psychology, 36*(3), 152-162.

Ladd-Taylor, M., & Umansky, L. (1998). *Bad mothers: Politics of blame in twentieth-century America*. New York: New York University Press

Law Commission of Ontario. (2012) Advancing equality for persons with disabilities Through law, policy and practice: A draft framework. Retrieved from: www.lco-cdo.org/disabilities-draft-framework.pdf.

Local-Immigration Partnership. (2014). Retrieved from: http://www.scarboroughlip.com/home/

MacRae, H. (1999). Managing courtesy stigma: The case of Alzheimer's disease. *Sociology of Health and Illness, 21*(1), 54-70.

Maloni, P. K., Despres, E. R., Habbous, J., Primmer, A. R., Slatten, J. B., Gibson, B. E., & Landry, M. D. (2010). Perceptions of disability among mothers of children with disability in Bangladesh: Implications for rehabilitation service delivery. *Disability and Rehabilitation, 32*(10), 845-854.

McDonald, J. T., & Worswick, C. (2012). The migration decisions of physicians in Canada: The roles of immigrant status and spousal characteristics. *Social Science & Medicine, 75*(9), 1581-1588.

McKeever, P., & Miller, K. L. (2004). Mothering children who have disabilities: A Bourdieusian interpretation of maternal practices. *Social Science & Medicine, 59*(6), 1177-1191.

Merrick, E. (1999). Like chewing gravel: On the experience of analyzing qualitative research findings using a feminist epistemology. *Psychology of Women Quarterly, 23*(1), 47-57.

Miles, M. B., & Huberman, A. M. (1994). *Qualitative data analysis: An expanded sourcebook*. Thousand Oaks: Sage Publications.

Moghadam, V. M. (2003). *Modernizing women: Gender and social change in the Middle East*. Boulder, Colorado: Lynne Rienner Publishers.

Moore, A., & Kornblet, S. (2011). *Advancing the rights of persons with disabilities: A US-Iran dialogue on law, advocacy and policy.* Retrieved from http://www.stimson.org/books-reports/advancing-the-rights-of-persons-with-disabilities-a-us-iran-dialogue-on-law-policy-and-advocacy/

Munhall, P., & Boyd, C. (1993). *Nursing research: A qualitative perspective.* New York: National League for Nursing.

Nasrallah, C. (2005). *Canada's approach to multiculturalism.* Italy: Department of Canadian Heritage.

Newcomer Toronto Fair. (2014). Retrieved from: http://www.newcomerscanada.ca/events/toronto/

Nwadiora, E., & McAdoo, H. (1996). Acculturative stress among Amerasian refugees: Gender and racial differences. *Adolescence, 31*(122), 477-487.

Ontario Immigration. (n.d.). Retrieved from: http://www.ontarioimmigration.ca/en/.

Osanloo, A. (2009). *The politics of women's rights in Iran.* Princeton University Press.

Immigration Portal, Overview. (n.d.). Retrieved from http://www1.toronto.ca/wps/portal/contentonly?vgnextoid=6fa6ba2ae8b1e310VgnVCM10000071d60f89RCRD

Ministry of Finance, (2006). *Census Highlights: Factsheet 1.* Retrieved from http://www.fin.gov.on.ca/en/economy/demographics/census/cenhi06-1.html

Patton, M. Q. (1990). *Qualitative evaluation and research methods*. Newbury Park, Calif.: Sage Publications.

Peterborough Partnership Council on Immigrant Integration. (2012). *Ontario pre-service teacher education: The case for equity, inclusion and diversity training.* Retrieved from: http://olip-plio.ca/wp-content/uploads/2013/03/Case-for-Equity-Inclusion-and-Diverstiy-Training.pdf

Picot, W. G. (2004). The deteriorating economic welfare of immigrants and possible causes. *Statistics Canada, Analytical Studies Branch.*

Picot, G., & Hou, F. (2003). The rise in low-income among immigrants in Canada, *Statistics Canada, Analytical studies branch research paper series, no. 198*.

Picot, W. G., & Sweetman, A. (2005). The deteriorating economic welfare of immigrants and possible causes*, Statistics Canada, Analytical Studies Branch.*

Portes, A., & Rumbaut, R. G. (1996). *Immigrant America: A portrait*. Berkeley: University of California Press.

Potvin, M. 2008. Racisme et ‘discours public commun’ au Québec. In S. Gervais, D. Karmis & D. Lamoureux. (Eds.), *Du tricoté serré au métissé serré? La culture publique commune au Québec en débats*. Québec: Presses de l’Université Laval.

Redfield, R., Linton, R., & Herskovitz, M.J. (1936). Memorandum for the study of acculturation. *American Anthropologist, 38*, 149-152.

Reissman, C. K. (1993). *Narrative Analysis*. Newbury Park: SAGE Publications.

Reitz, J. (2007). Immigrant employment success in Canada, part II: Understanding the decline. *Journal of International Migration and Integration, 8*(1), 37-62.

Rezai-Rashti, G. M. (2011). Iranian women's increasing access to higher education but limited participation in the job market. *Middle East Critique, 20*(1), 81-96.

Rezai-Rashti, G. M. & Moghadam, V. M. (2011). Women and higher education in Iran: What are the implications for employment and the “marriage market”?. *International Review of Education, 57*, 419-441.

Ringsberg, K. C., Lepp, M., & Finnstrom, B. (2002). Experiences by patients with asthma-like symptoms of a problem-based learning health education programme 3. *Family Practice, 19*(3), 290.

Rodriguez, D. (2009). Culturally and linguistically diverse students with autism. *Childhood Education*, 85, 313-317.

Ruffolo, M., Kuhn, M., & Evans, M. (2005). Support, empowerment, and education. *Journal of Emotional and Behavioral Disorders, 13*(4), 200-212.

Sajedi, F., Alizad, V., Alaeddini, F., Fatemi, R., & Mazaherinezhad, A. (2008). The effect of adding homeopathic treatment to rehabilitation on muscle tone of children with spastic cerebral palsy. *Complementary Therapies in Clinical Practice, 14*(1), 33-37.

Samadi, S.A. (2008). Comparative policy brief: Status of intellectual disabilities in the Islamic Republic of Iran, *Journal of Policy and Practice in Intellectual Disabilities*, 5, 129-132

Schutz, S. E. (1994). Exploring the benefits of a subjective approach in qualitative nursing research. *Journal of advanced nursing, 20*(3), 412.

Shahidian, H. (1999). Gender and sexuality among immigrant Iranians in Canada. *Sexualities, 2*(2), 189-222.

Silverman, D. (2006). *Interpreting qualitative data: Methods for analyzing talk, text, and interaction*. London; Thousand Oaks, California: SAGE Publications.

Singh, I. (2002). Bad boys, good mothers, and the 'miracle' of Ritalin. *Science in Context, 15*(4), 577-603.

Sirles, E. A., & Franke, P. J. (1989). Factors influencing mothers' reactions to intrafamily sexual abuse. *Child Abuse Neglect, 13*(1), 131-139.

Statistics Canada. (2004). Children with disabilities and the educational system: A provincial perspective. http://www.statcan.gc.ca/pub/81-004-x/2007001/9631-eng.htm.

Statistics Canada. (2006). Facts and figures: Immigration overview. http://www40.statcan.gc.ca/l01/cst01/demo34a-eng.htm.

Statistics Canada. (2008). Facts and figures: Immigration overview. http://www.cic.gc.ca/english/pdf/research-stats/facts2008.pdf.

Statistics Canada. (2011). Youth in Transition Survey. http://www23.statcan.gc.ca/imdb/p2SV.pl?Function=getSurvey&SDDS=4435.

Statistics Canada. (2013). http://www.statcan.gc.ca/tables-tableaux/sum-som/l01/cst01/demo02a-eng.htm

Statistics Canada. (2013). Migration: international, 2010 and 2011. *http://www.statcan.gc.ca/pub/91-209-x/2013001/article/11787-eng.htm*.

Statistics Canada. (2009). *Participation and Activity Limitation Survey (PALS).* Ottawa, Ontario: Statistics Canada. Ottawa, Ontario: Data Liberation Initiative.

Stiles, W. B. (1993). Quality control in qualitative research. *Clinical Psychology Review, 13*(6), 593-618.

Stromquist, N. P. (2006). Women's rights to adult education as a means to citizenship. *International Journal of Educational Development, 26*(2), 140-152.

Suarez-Orozco, M. (1991). Immigrant adaptation to schooling. In M. Gibson & J. Ogbu (Eds.), *Minority Status and Schooling: A Comparative Study of Immigrants and Involuntary Minorities*. New York: Garland Publishing, Inc.

Sue, D. W., & Sue, D. (2003). *Counseling the culturally diverse: Theory and practice (4th ed.).* New York: J. Wiley

Tajfel, H. & Turner, J. C. (1986). The social identity theory of inter-group behavior. In S. Worchel & L. W. Austin (Eds.),*Psychology of Intergroup Relations*. Chicago: Nelson-Hall.

Trainor, A. (2010). Diverse approaches to parent advocacy during special education home-school interactions. *Remedial and Special Education, 31*(1), 34-47.

Turnbull, A. Turnbull, R. Erwin, E.J., Soodak, L.C., & Shogren, K.A. (2011) . *Families, professionals, and exceptionality: Positive outcomes through partnership and trust.* New Jersey: Pearson Education.

U Reach Toronto. (2014). *Toronto newcomer services*. Retrieved from http://www.ureachtoronto.com/content/toronto-immigrant-services, June 20, 2014.

Weiss, R. S. (1995). *Learning from strangers : The art and method of qualitative interview studies*. New York: Free Press.

Welcoming and inclusive communities Accessibility Project. (2001). *Consultation report.* Retrieved from http://wiki.settlementatwork.org/w/uploads/Accessibility_Project_Consultation_Report_2011-.pdf

APPENDIX A

Consent Form

Individual and Focus Group Interview Consent Form

Research Project Title: **Motherhood, Immigration and Disability: Iranian Mothers' Access to Support in Toronto, Ontario**

Study Team:

This research is being conducted by Yasaman Jalali-Kushki, a doctoral student from the Department of Educational and Counselling Psychology at McGill University under the direction of Dr. Tara Flanagan. Yasaman can be reached at phone: (514) 994-6731/email: yasaman.jalali-kushki@mcgill.ca. Dr. Flanagan can be reached at phone: 514-398-3441/email: taradawn.flanagan@mcgill.ca.
You are being asked to participate in a research study. Please take your time to review this consent form and discuss any questions you may have, or words you do not clearly understand, with the research study team or staff.

Purpose of the Study

The purpose of this narrative study is to understand the experiences of Iranian immigrant mothers in accessing services for their children with disabilities in Toronto, Ontario, Canada. The experiences of immigrant Iranian mothers will be generally described as their perceived access to support from the point of immigration onwards, through narrative interviews and a photovoice project.

Study Procedures

This study involves two ways of interviewing individuals. We will be interviewing individuals, on a one-on-one basis, and asking questions about your experiences with immigration and accessing disability-related supports and services for your child. After this interview, we will ask you to take pictures of your experiences of support and services during a week. The second interview will take place by asking a group of people to come together into a focus group. In this group, we will look through pictures you may have taken during the week, and you will discuss, as a group, what your experiences are accessing supports and services for your children. The pictures you take will be used strictly for the focus group, and will not be published or used in any other way by the researchers. You will have the option to participate in a one-on-one interview, in a focus group, or in both. The interviews and focus groups will take place in Farsi, French or English language, as you prefer. Individual interviews and focus groups will be audio recorded, and any pictures taken with digital cameras for the purpose of the study will be saved by the researchers. All information you provide will be kept strictly confidential and will only be used to create a general picture of the experiences of Iranian immigrant mothers of children with disabilities in Toronto, Ontario.
We will also ask if you would be willing to be contacted at a later date in case we need to clarify any of the responses given in the interview. This would involve providing your name and email or phone number. All personal information you provide will be kept strictly confidential, separate from the interview data and kept on file for the duration of the study (June 2012 to June 2013). At the conclusion of this research project we will destroy all computer and paper records containing your identifying information.

Access to personal information will be restricted to Yasaman Jalali-Kushki, the primary researcher, only and will be secured electronically and physically in a locked office away from public access. No staff from any service organizations or communities will have direct access to your personal information. The same confidentiality will apply if university students and other researchers later use the data for a research project.
The interview will be one to two hours long. You can stop participating at any time in the interview or research process, and your data will be removed at your request.

Costs
The study procedures are conducted at no cost to you.

Benefits
There may or may not be direct benefit to you from participating in this study. When the research is completed, it will help the researchers to understand what supports can be offered to Iranian mothers of children with disabilities.

Compensation for Participation
You will be provided with transportation to the interviews and focus groups, and if needed, childcare will be provided. You will also be given a digital camera valued at $xxx to participate in the photovoice project.

Confidentiality
Information gathered in this research study may be published or presented in conferences, journals, and a doctoral thesis; however, this will not include photos or audio recordings, and your name or other identifying information will not be used or revealed. Despite all efforts to keep information shared in the focus groups confidential, there is a chance that a focus group participant may share the information they have heard. We therefore cannot guarantee absolute confidentiality.

Voluntary Participation/Withdrawal from the Study
Your decision to take part in this study is voluntary. You may refuse to participate or you may withdraw from the study at any time and remove all your data. Your decision not to participate or to withdraw from the study will not affect the services and support that you receive.

Questions
You are free to ask any questions that you may have about your rights as a research participant. If any questions come up during or after the study, contact the research team: Yasaman Jalali-Kushki phone: (514) 994-6731/email: yasaman.jalali-kushki@mcgill.ca or Dr. Flanagan phone: 514-398-3441/email: taradawn.flanagan@mcgill.ca.
Do not sign this consent form unless you have had a chance to ask questions and have received satisfactory answers to all of your questions.

Statement of Consent
Participant:

I have read this consent form. I have had the opportunity to discuss this research study with an investigator of the research study team. I have had my questions answered by them in the language I understand. The risk and benefits have been explained to me.

☐ I **consent** to participate in the research study **Motherhood, Immigration and Disability: Iranian Mothers' Access to Support in Toronto, Ontario.**

I (check one or more) **consent** to participate in: 1) ☐ an **individual interview**; 2) ☐ a **focus group**; 3) ☐ **both**

I (check one only) ☐ **consent** ☐ **do not consent** to being contacted at a later time for any clarification required for the interviews.

I (check one only) ☐ **consent** ☐ **do not consent** to providing the name, address, and phone number of contact people for the study team to contact in the event of a move or if a phone number changes

By signing this consent form, I have not waived any of the legal rights that I have as a participant in a research study.

Participant Signature: ________________________________ Date: ______________
Participant Printed Name:____
Participant Address (if consented to provide): __________________________________
____
____
Additional Contact Name and Address: (if consented to provide)
____
____

Research Staff

I, the undersigned, have fully explained the relevant details of this research study to the participant named above and believed that the participant has understood and has knowingly given their consent.

Printed Name: ____Date: _____________
Signature: ____________________Role in the Study: __________________________

APPENDIX B

English Recruitment Flyer

PARTICIPANTS NEEDED FOR RESEARCH IN IMMIGRATION AND DISABILITY

We are looking for volunteers to take part in a study of
the experiences of **Iranian immigrant mothers** in accessing services for their
children with disabilities in Toronto, Ontario, Canada

As a participant in this study, you would be asked to:

Participate in a one-on-one interview and/or a focus group

Your participation would involve one or two sessions that will last approximately 1-2 hours each.

In appreciation for your time, you will receive
a digital camera valued at $70.

For more information about this study, or to participate in this study,
please contact:
Yasaman Jalali-Kushki, PhD Student

Department of Educational and Counselling Psychology

McGill University

at
416-837-6731

Email: yasaman.jalali-kushki@mail.mcgill.ca

Student of Dr. Tara Flanagan

Email: tara.flanagan@mcgill.ca

APPENDIX C

Farsi Recruitment Flyer

بررسی تجارب مادران ایرانی مهاجر در زمینهٔ دسترسی به خدمات و امکانات موجود

برنامهٔ تحقیقاتی

بررسی تجارب **مادران ایرانی مهاجر** در زمینهٔ دسترسی به خدمات و امکانات

موجود برای **فرزندان استثنائی آنها** در تورنتو، انتاریو

از شرکت کنندگان در این بررسی، انتظار می رود که در

یک جلسهٔ مصاحبهٔ خصوصی تک نفره و یا در یک گروه تخصصی شرکت نمایند

بدینترتیب همکاری شما شامل شرکت در یک یا دو جلسه خواهد بود که هرکدام ۱ تا ۲ ساعت طول می کشد

بعنوان قدردانی از همکاری شما، یک دوربین دیجیتال به ارزش 70 دلار به شما هدیه خواهد شد

برای کسب اطلاعات بیشتر و همکاری در این زمینه

با یاسمن جلالی کوشکی، دانشجوی دکترا

دپارتمان Educational and Counselling Psychology

دانشگاه McGill

تماس بگیرید

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