

Barriers to Health Service Utilization by Immigrant Families
Raising a Disabled Child:
Unmet Needs and the Role of Discrimination

Final Report to
Citizenship and Immigration Canada

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EXECUTIVE SUMMARY

This two-part, mixed methods study assessed attitudinal, policy, and practice barriers to health service utilization by immigrant parents from Asia, Africa, and the Caribbean who are raising a disabled child or youth in the Greater Toronto or Hamilton areas. The project was based on a critical review of the literature on immigrant/refugee families raising a child with a disability, which indicated that very little is known about the health and social service access, utilization, and service care experiences of these families, particularly in the Canadian context (King, Esses, & Solomon, in press). Directions identified for research included the need for comparative studies involving different immigrant populations, in order to determine common and unique barriers and areas of unmet need related to ethnicity.

The current project assessed the perceptions of three groups (representatives of community service organizations that provide support to newcomers, immigrant parents raising a child with a disability, and service providers employed by health care centres) regarding (a) barriers in service delivery for immigrant families, (b) extent of unmet needs, and (c) the extent to which services are culturally sensitive and family-centred, all of which are relevant to the issue of discrimination.

The first phase of research involved a qualitative assessment of perceptions of barriers and supports to service for recent immigrants raising a disabled child or youth. A total 9 focus groups and individual interviews were conducted to obtain information from several perspectives (pediatric service providers, immigrant group leaders, and immigrant parents) concerning issues regarding service access, utilization, and service care experiences, as well as helpful practices. The emerging themes included language, knowledge, and financial barriers to service delivery for these parents, the nature of their unmet needs, and the extent to which services are culturally sensitive

and family-centered. This information was used to clarify and improve on the nature of questions to address in Phase 2 (the survey phase).

The second phase involved a survey of immigrant families raising a child with a physical disability, which assessed families' needs and experiences regarding health services. The survey involved families from Asia (excluding the Middle East), Africa, and the Caribbean who have a child with a progressive or nonprogressive physical disability and who receive services from pediatric rehabilitation organizations in the Toronto or Hamilton areas. Over 130 organizations were approached and 42 agreed to help with recruitment. Unfortunately, the number of completed surveys was less than desired, due to issues encountered in recruitment, including organizations' lack of resources to assist, a lack of eligible families, and language barriers. A total of 15 parents responded to the survey; the findings are therefore preliminary and will be particularly useful in providing insights into important areas for future research.

The survey findings suggest that participants had higher levels of unmet needs than non-immigrant parents of children with disabilities (from published data in the United Kingdom), particularly with respect to needing help finding available services, advocacy, and day to day support for their child. The parents who responded to our survey also reported significantly lower levels of family-centred care when compared with published data from non-immigrant parents of children with disabilities in Ontario, particularly with respect to Enabling and Partnership, and Coordinated and Comprehensive Care. The findings also suggest that integration-related variables affect the health care experiences of immigrant parents of children with physical disabilities. When these parents had extended family in Canada, they appeared to be less likely to report needing help with respect to emotional support. Compared to more recent immigrant families (those who had immigrated between 2006 and 2011), less recent newcomers (those who immigrated between 2000 and 2005)

had poorer perceptions of family-centred care. These findings require further research to establish their validity, but they provide the intriguing suggestion that different integration-related variables and acculturation processes are associated with experiences of unmet needs and of family-centredness in health care delivery.

The study team learned valuable lessons regarding future research with immigrant families of children with disabilities. The qualitative findings, in particular, provide important information for service organizations and policy makers regarding health service barriers experienced by immigrant families raising a disabled child, and will inform the development of policies and best practices. An article is currently being prepared for publication from this qualitative information and a second article is planned on methodological issues in quantitative research with immigrant families.

KEY MESSAGES AND RECOMMENDATIONS

Qualitative Study

- *Service provider training.* Service providers did not have any training in cultural competency and believed that this was increasingly important in working with immigrant families with children with disabilities. Training in culturally sensitive care as well as different perceptions of disability and health is important. Service providers need to be aware that immigrant families may not ask for help or alternative treatment options because of their perceptions of authority. When service providers and community service representatives have greater community connections, they are able to refer families to services available in the community.
- *Use of translators.* It would be beneficial for service providers to be trained on how to work with translators, to be aware of the language services available to immigrant families, and to be aware of the importance of using a translator in meetings with families. It is important to offer language support to families and not assume that the family knows that such support exists.
- *Service providers from diverse backgrounds.* Hiring service providers from diverse backgrounds may be a useful strategy to break down barriers between immigrant families and service providers.
- *Taking extra time with immigrant families.* Immigrant families need extra time to be able to ask questions. Service organizations should consider giving explicit permission to service providers to take the extra time to talk with immigrant families about their health histories and their contexts before immigrating to Canada. It is important not to assume that families have knowledge of the services, supports, equipment, funding, and possibilities for their children.
- *The importance of support.* Community services need to support the creation and maintenance of immigrant parent support groups for parents who have a child with a disability. Service providers need to be aware of parent support groups and refer families to them.

- *Help in navigating the system.* If possible, service providers should link immigrant families with a social worker or settlement worker who can help them navigate the system, including finding services, helping them fill out forms, and getting them supports.
- *Home visits.* Families have positive experiences when services come to them and they receive services in their homes.

Quantitative Survey

- Immigrant/refugee families of children with physical disabilities are a very vulnerable group. Comparisons between the study sample and published data for parents in the U.K. indicated greater rates of unmet need in immigrant families with a child with a physical disability in comparison to non-immigrant families of children with disabilities.
- The immigrant parents reported receiving lower levels of family-centred care (on a standardized measure of family-centred care) in comparison to Ontario parents of children with disabilities. This was particularly the case with respect to Enabling and Partnership, and Coordinated and Comprehensive Care.
- More recent newcomers (in the last 5 years) had more positive perceptions of receiving family-centred care than did less recent newcomers (6 to 10 years in Canada), perhaps due to lower expectations based on the health care systems of their countries of origin. Over time, they may begin to perceive the barriers to services and their expectations may rise, creating the perception of services as being less family-centred. The fact that many of the families came to Canada as refugees and are low in education achievement and household income likely exacerbates the barriers reported in this survey.

Policy Implications

- Immigrant parents of children with physical disabilities have multiple disadvantages. They are disadvantaged due to newcomer status, having a disabled child, and social issues such as poverty and discrimination.
- The findings clearly indicate that immigrant parents encounter issues in accessing services due to language, knowledge, and economic barriers. Once they have accessed services, they still indicate high levels of unmet needs, particularly for information about available services, advocacy, and day to day support for their child. Immigrant parents with extended family in Canada may fare better, due to the informational, emotional, and practical support they receive from family members.

A. Need for Research on Immigrant Families Raising a Child with a Disability

Population based surveys indicate that access to health care is influenced by ethno cultural factors (Newacheck, Stoddard, & McManus, 1993). Little is known, however, about the health and social service access, utilization, and service care experiences of immigrant and refugee families raising a child with a chronic health condition (physical disability or illness), mental health disorder, or developmental disability, hereafter referred to as “disabling conditions” or “disabilities.” In a 60-page report and literature review on the experiences and needs of refugee and asylum seeking children in the United Kingdom (Hek, 2005), a single paragraph is devoted to those with disabling conditions. Given the growing number of immigrant families residing in North America and Europe, more information is needed to guide service providers and inform policymakers about the best ways to meet the needs of newcomers whose children have disabilities (Cho, Singer, & Brenner, 2003).

Immigrants and refugees experience complex issues affecting their access and utilization of services, as well as their experiences of care. They face issues of poverty, single parenthood, stressors associated with resettlement, social exclusion, and under and unemployment (Blacher et al., 1997; Esses et al., in press; Hernandez, 2004). Refugees and asylum seekers with disabilities are among the most socially and economically disadvantaged members of society (Harris, 2003). An extensive body of literature indicates that immigrant families experience poverty and low income levels, and points to the need for policies and programs to assure their children’s health, educational success, and well-being (e.g., Hernandez, 2004; Rhoades, Price, & Perigoe, 2004). Similarly, the literature on childhood disability indicates that children with a variety of chronic conditions—such as cerebral palsy, spina bifida, autism, and epilepsy—experience a high level of

unmet needs and face significant barriers to health care (Mayer, Skinner, & Slifkin, 2004; Newacheck et al., 1998; Silver & Stein, 2001).

Review of Existing Literature

A review of the literature on immigrant and refugee parents' and children's access to, utilization of, and experiences or evaluations of (i) primary health services, (ii) social assistance services, (iii) rehabilitation services, and (iv) mental health services identified a total of 21 articles, theses, reports, and book chapters published after 1990 dealing with immigrant/refugee families' experiences with service systems when raising a child with a disabling condition (King et al., in press). The majority of these reports examined or discussed a mix of ethnic populations or did not specify a particular population ($n= 10$). Five reports (largely Canadian) focused on Chinese immigrants, four reports from the United States dealt with Mexican or Latin American immigrants, and the remaining two reports focused on Korean and South Asian immigrants to the United States. The literature was widely mixed with respect to type of childhood disability. Reports dealt primarily with 'unspecified/diverse' disabilities ($n= 8$), followed by mental health difficulties ($n= 4$), developmental disabilities ($n= 3$), and autism ($n= 2$). There were single reports on immigrant/refugee children with chronic illness, deafness, speech difficulties, and diabetes.

The review indicated three overarching areas of interest in the literature: (a) how culture has its effects on decisions involving services (general factors), (b) socio-cultural barriers to seeking services and service utilization, and (c) socio-cultural factors facilitating service access and utilization. The most attention was given to outlining theories and mechanisms by which cultural factors influence the 'service experience' in its broadest sense. Each ethnic group experiences a unique mix of cultural roles, expectations, and conceptual frameworks that influence how its members view their support systems and communities, as well as their perceptions of services

(Groce & Zola, 1993). Among the more general cultural factors affecting familial response to disability and the service care experience are beliefs regarding the etiology of disability; societal and familial attitudes towards disability; and family roles, responsibilities, and expectations.

Second, the literature outlines many factors contributing to the widespread tendency of cultural minorities to avoid engaging outside help, including (a) unfamiliarity with systems, (b) lack of knowledge of services, (c) perceptions of the roles of service providers and families, (d) communication issues, and (e) culturally incongruent service delivery systems (Albright, 1997).

The major barriers to service access and utilization are (a) language barriers, leading to lack of awareness of services and lack of understanding of service providers' recommendations, (b) financial and economic barriers, (c) immigrants' assumptions and preconceived notions about services, leading to fears regarding stigma and other negative outcomes, and (d) service providers' assumptions and lack of understanding of culturally-influenced attitudes, beliefs, and behaviors.

Third, the literature explicitly considers three socio-cultural factors as positive influences on the service care experience of immigrant families: access to resources congruent with beliefs; social support; and familiarity with the values, beliefs, language, and customs of the larger society.

Summary of the Literature

The literature predominantly focuses on understanding how culture shapes attitudes, beliefs, and expectations and thereby affects help seeking, decisions involving services, and service care experiences. In addition to these belief-related factors, the literature also focuses on linguistic barriers to equitable access to services. Language has multiple interacting influences on service use—affecting awareness of available resources, comfort and willingness to seek out resources and services, acceptance of services, engagement in the family-professional relationship, and follow

through with recommendations. Other barriers to services include financial and economic barriers, fears regarding stigma and other negative outcomes, and service providers' lack of awareness and sensitivity. Very little attention has been paid to factors that *enhance* the service delivery process for immigrant families raising a child with a disability. There has also been very little research on the influence of cultural values, beliefs, and identity on service access and use; their influence on engagement with service systems therefore deserves exploration.

B. Research Gaps

Our review indicated many gaps in our understanding of immigrant families raising a child with a disability, and therefore many important questions to be addressed by research (Skrinda, 2008), including research on fathers' perspectives, children's outcomes, the processes influencing outcomes, service systems, cross-cultural comparisons, and disabled refugee children and their families. The present proposal focuses on two of these areas: service systems and comparisons of three first-generation immigrant populations (i.e., Asian, African, and Caribbean). These groups were chosen for several reasons: (a) the study focus on issues of discrimination, (b) they are representative of the Canadian immigrant population in the Greater Toronto and Hamilton areas, (c) they are appreciable in number, and (d) they are very different from one another. Future studies involving other populations are planned.

Service Systems

There is a large gap in our knowledge of the ways service organizations and systems respond to the needs of various immigrant populations. Research is needed to simply describe the service integration efforts that have been made to deal with barriers to awareness, access, and use, and to uncover effective practices for immigrant families raising a child with a disabling condition. We also lack knowledge of the experiences of service providers in various types of service organizations.

What have they found to be effective ways of dealing with the issues they face, and what strategies do they use to engage immigrant families who have a child with a disability? Service providers could be surveyed or interviewed to determine their personal and professional concerns and their support and resource needs with respect to providing services (Skrinda, 2008).

Furthermore, little is known about the perceptions of family-centred or culturally sensitive care from the point of view of immigrant parents raising a child with a disabling condition (Dix et al., 2009). Culturally sensitive care is generally discussed in terms of the approaches, attitudes, and behaviors of service providers (e.g., Fong, 2004) and is similar to the notion of family-centred care, which is used in the childhood disability literature (Rosenbaum et al., 1998). Both involve respectful and supportive treatment, information provision, and individualized care that consider the beliefs, worldviews, and preferences of families.

Comparative Studies

There is a need for research providing ethno specific comparisons of immigrant families' service care experiences when raising a child with a disabling condition. There is a substantial gap in our knowledge of the relative influence of ethnicity, new settlement, and childhood disability on child, parent, and family service needs and outcomes. Addressing this issue requires study designs that provide comparisons of various ethno specific immigrant families with and without children with disabilities, taking into account their degree of familiarity with the host culture (Albright, 1997; Ali et al., 2001). Comparisons to parents of other ethnic groups and parents of children with other disabilities will provide a nuanced understanding of the relative and additive roles of particular cultural beliefs and practices, as well as particular child needs related to disability. There is a need for an ethno cultural and systems approach to understand the interacting factors that influence children, families, service providers, and service organizations (Lerner, 1998; Overton, 1998).

C. Theoretical Approach

Several theoretical frameworks guided our proposed research, including (a) ecocultural theory, which considers the sociocultural environment of the child and family and how it impacts on family dynamics (Gallimore et al., 1996), and (b) theoretical models that combine coping-stress process models with concepts from ecological-contextual theories, positing that ethnicity provides a context for caregiving (Dilworth-Anderson & Anderson, 1994).

Broad conceptual approaches that will guide our interpretation of findings include a socio-ecological approach, which points to the importance of considering environmental, family, and child-related factors (Bronfenbrenner & Ceci, 1994), and family-centred service, considered to be a best practice approach in early intervention and rehabilitation services for children with disabilities and their families (Bailey et al., 1992; King et al., 2002; Rosenbaum et al., 1998). There is an extensive literature on client- and family-centred care, which outlines how clients/families want to be treated in the service delivery process (e.g., Moore & Larkin, 2006; Sumsion & Law, 2006). A social inclusion framework incorporating principles of access and equity will be used to inform recommendations (Omidvar & Richmond, 2003; Skrinda, 2008).

D. Rationale for Focus on Particular Immigrant Populations and Conditions

Based on our literature review, it was important to focus on immigrant groups raising children with particular types of disabling conditions, in order to begin to attempt to disentangle their influences on expectations and perceptions of service delivery systems, and experiences of service care. We focused on first-generation immigrant families in the Hamilton and Toronto areas from Asia (excluding the Middle East), Africa, and the Caribbean. Asian families represent one of the fastest-growing segments of Canada's population (Statistics Canada, 2008). A group of 22 Asian countries were included (China, Taiwan, Japan, Korea, Hong Kong, Vietnam, Burma, Cambodia, Laos, Thailand,

Malaysia, East Timor, Indonesia, Singapore, Philippines, Bangladesh, Bhutan, India, Maldives, Nepal, Pakistan, and Sri Lanka). (We excluded the Middle East because individuals from Middle Eastern countries may receive different treatment due to existing stereotypes, and because inclusion would widen the breadth of groups in the Asian category too much.) African and Caribbean immigrant families are also appreciable in number. These groups are very different and will provide useful and informative points of comparison. We focused on newcomers (i.e., 1-10 years' residence in Canada) (Dunn & Dyck, 2000) who speak English, and who therefore face barriers unrelated to language. In addition to access-related factors, we focused on psychosocial and interpersonal communication barriers occurring in face-to-face client-practitioner interactions, which are considered to be a major factor influencing healthcare disparities and health outcomes (Penner et al., 2007).

Physical disabilities refer to chronic conditions associated with physical functional limitations, including non-progressive conditions such as cerebral palsy and spina bifida, and progressive conditions such as muscular dystrophy. We have chosen to focus on families receiving services for their child in one of two geographical locations (Toronto and Hamilton). Families may have different issues regarding access and utilization and different service care experiences due to the nature, number, location, structuring, and format of services available in different geographical areas.

PHASE 1: FOCUS GROUPS AND INDIVIDUAL INTERVIEWS

A. Overview

The first phase assessed barriers to service for immigrants in our target groups from the perspectives of representatives of community service organizations that provide support to newcomers, immigrant parents of children with physical disabilities, and service providers employed by children's health care centres. The intent of the focus groups and interviews was to obtain information from several perspectives about issues regarding service access, utilization, and service care experiences, as well as helpful practices.

Using established relationships with children's rehabilitation services and immigrant organizations in Toronto and Hamilton, we invited service providers and community service organization representatives to attend focus groups and also invited immigrant parents to take part in individual interviews. When service providers and community service organization representatives were interested in taking part but could not attend a scheduled focus group, we held individual interviews with them. The focus groups and interviews assessed barriers to services, perceptions of culturally sensitive and family-centred (i.e., individualized and respectful) care, and the ways in which health service organizations respond to the needs of various populations (including translation services, outreach services, provision of service coordination, and service integration). These are all important topic areas identified in our critical review of the literature. The qualitative data were also used to clarify and improve on the nature of questions to address in Phase 2 (the survey phase), as well as obtain information about how to best recruit participants for that phase.

B. Methodology

Ethical Approval and Recruitment

Ethics approvals for both phases of the project were obtained from Holland Bloorview Kids Rehabilitation Hospital and McMaster University. Participants were recruited through an introductory email and information package sent to key informants by the Project Coordinator. We solicited the participation of service providers from Holland Bloorview Kids Hospital and McMaster Children's Hospital with backgrounds in social work, physical therapy, psychology, occupational therapy, speech-language pathology, family medicine, or developmental pediatrics who have experience delivering pediatric rehabilitation or primary care services to immigrant families raising a child with spina bifida or cerebral palsy. Participants with a mix of disciplinary backgrounds were included to ensure inclusion of different service delivery perspectives. Criteria for selection were (a) at least 2 years of experience working with children with disabilities, (b) at least one year of experience working with immigrant families.

Immigrant parents were recruited with the assistance of service providers at Holland Bloorview Kids Rehabilitation Hospital and McMaster Children's Hospital, in accordance with strict ethical guidelines regarding initial contact. Criteria for selection were (a) 1 to 10 consecutive years in Canada (to ensure some familiarity with the healthcare system and can provide information about barriers and supportive factors, but are still considered 'newcomers'), (b) immigrated from Asia, Africa or the Caribbean; (c) have a child with a disability, and (d) English-speaking (so that language barriers are minimized, allowing us to focus on psychosocial and interpersonal communication barriers). Community service organization representatives were solicited through personal contacts and by email invitation with known community service organizations in Toronto and Hamilton.

Participants

Focus groups and individual interviews were held with service providers and community service organization representatives in each location (Hamilton and Toronto). Individual interviews were held when there were difficulties in scheduling common times for all those interested in participating. As well, individual interviews were held with immigrant families raising a child with a disability.

All participants were selected on the basis of 'key informant' status and their ability to speak English. The service providers all had experience delivering pediatric rehabilitation services to immigrant families raising a child with a disability. The community organization representatives were from organizations such as community health centres or non-governmental organizations that provide health care support to newcomers (i.e., organizations with an interest in service delivery for children with disabilities).

As shown in Table 1, a total of 17 participants took part in Phase 1 (13 from Toronto and 4 from Hamilton). A total of 7 interviews and 2 focus groups were held. The 2 focus groups were held in Toronto: one with 6 service providers from Holland Bloorview Kids Rehabilitation Hospital, and the other with 4 representatives of Toronto-based community organizations. In addition, one individual interview was held with a Toronto community service organization representative, one with a Hamilton service provider, and one with a Hamilton community service organization representative. In Hamilton, individual interviews were held with two parents/families receiving services from McMaster Children's Hospital (a mother and father from China, and a mother from Somalia). In Toronto, two interviews were held with parents receiving services from Holland Bloorview (one mother from Haiti and one from East India).

Table 1: Focus Groups and Interviews

Name of Interview/Focus Group	Participants
Focus Groups	
Holland Bloorview Service Provider Focus Group	6 health care professionals, service providers from Holland Bloorview Kids Rehabilitation Hospital
Representatives of Toronto Community Organizations Focus Group	4 participants from Spina Bifida Association of Canada, Easter Seals Canada, Afghan Women's Association, and Moeen Centre for Physically Disabled and Developmentally Challenged Young Adults
Interviews	
Hamilton Community Service Organization Representative Interview	Program manager in the field of recreation at YMCA Hamilton
Hamilton Service Provider Interview	Pediatrician from McMaster Children's Hospital and Refugee Health Clinic
Toronto Community Service Organization Representative Interview	Settlement worker who works with newcomers with a disability
Interview with Chinese Family in Hamilton	Mother and father
Interview with Somali Family in Hamilton	Mother at the Children's Development and Rehabilitation Program
Interview with Haitian Family in Toronto	Mother at Holland Bloorview
Interview with East Indian Family in Toronto	Mother at Holland Bloorview

Background Information Surveys

Relevant background information was collected from all participants using background information surveys. We used a service provider background information survey to capture information about discipline, years in practice, and years of experience with immigrant populations and children with physical disabilities. A community service organization representative background information survey was used to capture information about their organization, length of time in Canada, populations of immigrants they have had experience with, etc. A parent background information survey was used to capture information about the length of time each participant has been in Canada, country of origin, gender, language spoken at home, whether they have a child with a disability (and, if so, whether the child was born in Canada and the nature of their disability), and

English language ability. The interviewer also made an assessment of the parents' English language ability (fluent/not very fluent).

Focus Groups and Individual Interviews

Each focus group followed a semi-structured guide involving open-ended questions. The individual interviews with parents also followed a semi-structured guide and involved open-ended questions to provide an in-depth narrative of personal experiences with healthcare services for their child and their perception of supports and barriers to health care utilization. All focus groups and interviews were conducted by the Project Coordinator and audio taped for analysis.

Focus group and interview questions. The questions consisted of a series of open-ended questions and more detailed prompts and probes. These included the nature of met and unmet needs; barriers and facilitators to healthcare utilization; service issues; service integration issues; and perceptions of culturally sensitive and family-centred (i.e., individualized and respectful) care. We also explored perceptions of the ways in which health service organizations respond to the needs of various populations, including the availability and extent of use of translation/interpreter services; availability and use of outreach services; and provision of service coordination. In addition, we obtained the advice of participants regarding aspects of Phase 2, such as how to best approach participants, and revisions to the background information form and the parent survey.

Transcription. Audio recordings of the focus groups and interviews were transcribed verbatim by an experienced transcriptionist. All identifying information was removed. The Project Coordinator reviewed the transcripts to correct errors and ensure that all identifying information was removed.

C. Qualitative Analysis

The project drew on interpretive traditions within qualitative research where an in-depth understanding of the participants' experiences will be developed (Patton, 1990; Strauss & Corbin, 1998). Team members read through each transcript several times and noted emerging themes and patterns. Themes were identified concerning issues of service access, service utilization, and service care experiences. Direct quotes from the interviews and focus groups were abstracted from the transcripts and given a code. The codes helped us to identify the sub-themes that emerged from the transcripts. The whole context of the interview or focus group was considered when abstracting statements and labelling them with codes (Graneheim & Lundman, 2004). We compared and contrasted the themes emerging for community service organization representatives, service providers, and parents.

D. Findings

Six major themes emerged from the analysis of the interviews and focus groups. These themes include language, knowledge, and financial barriers to service delivery to immigrant parents, the nature of their unmet needs, and the extent to which services are culturally sensitive and family-centered.

1. Language barriers

Translators and translation. Two of the interviewed parents indicated that they struggled with English at the time their child was diagnosed. These two parents were not aware that they had access to a translator during meetings with doctors and other health care professionals. Both of these participants believed that they would have been able to make better decisions regarding their children's treatment if they had used a translator in meetings with doctors. One of the participants admitted she only understood about half of what the doctors explained to her, which affected her

ability to make some decisions. Similarly, the service providers and community organization service representatives commented on the limited use of translators or other language services, and found it distressing that people do not consider translation an important part of providing health care. It was suggested that there needs to be education of health care professionals on the importance and use of translators or the language line in hospitals, and on how to work with interpreters. Reliance on family members to interpret was considered problematic. A neutral third party—a professional interpreter—was considered necessary to ensure correct interpretation of both words and meaning.

Cultural language. One mother explained that barriers not only exist because of the language spoken, but also the cultural meaning behind words and terms. Community service representatives also commented on the importance of understanding cultural differences in the meaning of language.

Language barriers lead to lack of understanding of service providers' recommendations. Parents indicated that they agreed to treatment decisions for their child that they were uncomfortable with because they could not communicate their worry or ask about alternative options. At other times, parents were resistant to services because they did not understand what was being offered.

2. Navigating the System

Unfamiliarity with the system. One of the major barriers for immigrant families is lack of knowledge about how to seek health care. Families may lack knowledge of primary care or not know that the family doctor is important in providing entry into the system. Finding a family doctor, the entryway into the Canadian health care system, can be difficult for families and may lead to a delay in getting treatment for their child. Basic issues may need to be addressed, such as understanding a bus route or how to use the subway. The Toronto service representative focus group members agreed that

immigrant families need personalized support through community networks and home visits that help them navigate the system.

Lack of knowledge of disability-related services. The majority of the interviews and focus groups pointed to the lack of knowledge among immigrant families of the services available to them. The Toronto community service representatives believed that health care providers need to understand that some newcomers come from places where they had very little support, care, or services. Simply giving parents the information may not be enough if they do not know what the information means. Another major theme was lack of knowledge among immigrant families about the possibilities for their children. Parents spoke about being happy, grateful, and amazed when they realized the possibilities available for their children in Canada. Families are in the process of learning the system, including how to get services through informal channels, such as family and friends as well as community organizations. One community service organization representative indicated that many referrals for recreation are from informal networks, particularly other families.

Perceptions of the roles of service providers and families. Immigrant families may not be used to a family-centered health care model and see the doctor and medical system as an authority or expert. The focus group of Toronto service providers indicated that newcomer parents often have expectations that health care providers will make decisions because they are experts. One of the mothers interviewed thought that her input was not needed because she had faith in the system. Another mother agreed to surgery for her son even though she was uncomfortable with it because she believes the doctors are the experts. Families may not discuss their fears or explore treatment options because they fear authority or because they come from countries where authority is not questioned. This can prevent them from asking questions when they do not understand something or from participating in decision making.

Many immigrant families feel that they have to accept the health care provided for them because it is a privilege to have health care. Service providers in Toronto suggest that, from their experiences, newcomer families, who often come from resource poor countries, often feel they need to accept everything and not question health care decisions because they are so fortunate to have access to health care for their child. One mother explained that she felt like she needed to be grateful for services and not ask for adjustments. On the other hand, some families rejected Western models of health care and searched for alternative means to treat their children.

3. Financial and Economic Barriers

Funding for equipment and services. The service provider focus group in Toronto suggested that newcomer families with a limited income struggle more because they have to find funds for equipment and other services for their child. Service providers believed that many immigrant families do not know about the funding that is available to buy equipment needed for their children or services that are not covered under OHIP.

4. Discrimination and culturally appropriate care

Discrimination. Language barriers may lead to discrimination. One community service representative in Toronto suggested that immigrant families get discriminated against because of their language limitations: service providers might not be patient with families that struggle with English or use interpreters. However, while service providers and community service representatives believe that immigrant families experience discrimination, none of the four families interviewed explicitly said they felt discrimination. One parent indicated that she had not experienced discrimination and rather believes there are cultural misunderstandings.

Perceptions of disability. One mother believes that it is God's will that her son has a disability; another family believes that with non-Western treatment their child will be "normal." From the perspective of service providers in Toronto, there is no clear distinction among some newcomers between being sick or being disabled. A community service representative in Toronto also suggested that disability is seen by many immigrants as an illness.

Culturally sensitive care. It is important to consider gender relations when working with immigrant families. One mother suggested that among Muslims it is the men who make the decisions, not the women, and the husbands are expected to ask questions and receive information. The service providers also acknowledged that newcomer children are not often involved in decision making, contrary to family-centered care principles.

Both Hamilton and Toronto service providers believe that extra time needs to be taken with immigrant families to understand their family contexts and histories, including their experiences and perceptions of health care. The community service representatives also believed that more time needs to be spent with immigrant families to really understand their needs. The provision of alternative treatment options was particularly important to one family, who sought treatment for their daughter in China because the kind of treatment they wanted was too expensive and less rigorously administered in Canada.

5. Support

All of the mothers interviewed discussed issues surrounding support. One mother said she had many family members to support her, but she was worried about what will happen to her son when she dies. None of the parents are members of a parent support group, but four of the five wished

they were part of such a group. Another mother believes that mothers need support from other parents to exchange information and to let their children have fun.

6. Positive experiences with health care and other service provision

Third party to help navigate the system. In the majority of the interviews and focus groups, the participants suggested that it is beneficial to have a third party help immigrant families to navigate the system. Service providers in Toronto thought that newcomers should be linked with families in similar circumstances and speaking the same language in order to orient them to the system. For families, having a third party such as a social worker to help them navigate the system was associated with positive experiences in accessing services, supports, and funding. One mother described the supports and services she received due to the help of a social worker. The social worker first helped to get her family's basic needs met, and then found her a translator who could help her at her son's doctor appointments and meetings with his teacher. Another mother suggested that home visits by a social worker when families first arrive in Canada would be helpful.

Home visits. Some of the community representatives and service providers believed that home visits with new immigrant families helps to build the relationship between service providers and families and also introduces the services available to the families. A Hamilton community service representative was especially keen on the importance of home visits, believing home visiting to be a best practice when working with immigrant families. Home visits engage the families and build trust, and give the service provider knowledge of the whole family and their environment. Parents all had positive experiences with services when the services came to their homes. A mother commented that she would not know about respite services unless they came to her.

E. Implications for Service Providers

Service Provider Training

Service providers in our sample reported that they did not have any training in cultural competency and believed that this was increasingly important in working with immigrant families with children with disabilities. Training in culturally sensitive care and different perceptions of disability and health is important. Service providers need to be aware that immigrant families may not ask for help or alternative treatment options because of their perceptions of authority. When service providers and community service representatives have greater community connections, they are able to refer families to services available in the community. Families often do not even think about what might be available when they are newcomers because it is not really conceivable. Learning about possible services takes time.

Use of Translators

It would be beneficial for service providers to be trained on how to work with translators, to be aware of the language services available to immigrant families, and to be aware of the importance of using a translator in meetings with families. It is important to offer language support to families and not assume that the family knows that such support exists.

Service Providers from Diverse Backgrounds

Hiring service providers from diverse backgrounds may be a useful strategy to break down barriers between immigrant families and service providers.

Take Extra Time with Immigrant Families

Immigrant families need extra time to be able to ask questions. Service organizations should consider giving explicit permission to service providers to take the extra time to talk with

immigrant families about their health histories and their contexts before immigrating to Canada. It is important not to assume that families have knowledge of the services, supports, equipment, funding, and possibilities for their children.

Support

Community services need to support the creation and maintenance of parent support groups for immigrant parents who have a child with a disability. Service providers need to be aware of parent support groups and refer families to them.

Third Parties to Help Navigate the System

If possible, service providers should link immigrant families with a social worker or settlement worker who can help them navigate the system, including finding services, helping them fill out forms, and getting them supports.

Home Visits

Families have positive experiences when services come to them and they receive services in their homes.

PHASE 2: SURVEY OF UNMET NEEDS, SERVICE EXPERIENCES, AND FAMILY-CENTRED CARE

A. Overview

The objective of this phase was to survey immigrant families raising a child with a physical disability. In partnership with Holland Bloorview Kids Rehabilitation Hospital, McMaster Children's Hospital, and organizations that support immigrant health care needs, we recruited participants by using flyers advertizing the study and indicating how to access an on-line version of the survey.

This survey, created using Survey Monkey, was accessible via the Holland Bloorview website. Paper versions of the survey were also made readily available to participants. Recruiting organizations were provided with hard copies and stamped addressed envelopes for their return.

The aim was to recruit samples of 30 Asian, 30 African, and 30 Caribbean parents raising children with physical disabilities.

The survey booklets contained three sections, capturing (a) background information about families and their immigration to Canada, (b) information about families' needs and experiences regarding health services, and (c) a psychometrically sound measure of family-centred care, which has been translated into over 10 languages and used worldwide (the Measure of Processes of Care; MPOC-20). Analyses were conducted to determine differences in unmet needs and perceptions of family-centred care as a function of two integration-related questions: the length of time the family had been in Canada, and whether or not they had extended family in Canada. Comparisons in rates of unmet need were made with respect to survey data from over 1,000 families of children with disabilities in the UK (Beresford, 1995). Comparisons were also be made with MPOC-20 data reported in past studies with English-speaking parents of children with physical disabilities in Ontario (King et al., 1998; King, King, & Rosenbaum, 2004).

B. Methodology

Description of Survey

Background Information questions. These questions were based on the background information survey used in Phase 1, with questions added based on feedback from Phase 1 participants. The questions solicited (a) basic descriptive information that was used to describe the sample of participants (e.g., country of origin, length of time in Canada; language spoken at home; age and gender of their child with a disability; the nature of their child's physical disability (non-progressive physical disabilities, including juvenile arthritis, acquired brain injury, cerebral vascular accident/stroke, orthopedic condition, spinal cord injury, amputation, cerebral palsy, spina bifida; progressive physical disabilities, including neuromuscular disorders); whether pediatric rehabilitation services were received from Hamilton or Toronto, and (b) questions capturing variables used in comparative analysis of the survey data (e.g., length of time in Canada and other indicators of "integration" such as whether families have extended family members who have been in Canada for a longer period of time).

Questions about immigrant families' needs and experiences regarding health services. We developed a number of items appropriate for first-generation immigrant families raising a child with a chronic disability. These items were based on questionnaires capturing of the experiences of immigrant families raising a child with a disability (Chamba et al., 1999), the needs of families raising a child with a disability (Bailey & Simeonsson, 1988), and client satisfaction and the provision of services (Larsen et al., 1979; Schmidt et al., 2007). This part of the survey also captured information regarding trust in the healthcare system and parents' perceptions of their interactions with service providers (including feeling listened to and supported), based on aspects of service provider-client interaction identified as crucial to the experience of health disparities (Penner et al., 2007). The survey contained both positively and negatively worded items, in order to avoid response bias and

give people a chance to express their true feelings. The nature of specific items and their wording was refined based on the information obtained from the focus groups in Phase 1 and the piloting phase (described below). These questions fell into five subsections: Services Received, Service Satisfaction, Positive Interactions with Service Providers, Challenges or Concerns, and Needs of Child and Family.

Measure of Processes of Care (MPOC-20). This is a widely used 20-item measure of caregiver perceptions of therapists' family-centred behavior, with good reliability and validity (King et al., 2004). This self-report questionnaire measures parents' perceptions of the extent to which specific behaviors of healthcare providers occur, including Enabling and Partnership, Providing General Information, Providing Specific Information about the Child, Coordinated and Comprehensive Care, and Respectful and Supportive Care. Each scale has good internal consistency (Cronbach's alphas over .80) and evidence of concurrent and discriminative validity. MPOC-20 or its' parent version MPOC-56 have been translated into 12 languages, including French, Thai, and Japanese, but not languages appropriate for the present study.

Piloting of the Survey

A separate piloting phase was conducted involving three immigrant families receiving services from Holland Bloorview Kids Rehabilitation Hospital. The Project Coordinator sat with parents as they completed the survey and took notes of any issues or uncertainties they expressed. The intent of this phase was to ensure that the survey was understandable, not overwhelming in terms of length, and not disrespectful in any way.

Recruitment Procedure

As suggested in past studies (Davies et al., 2009; Huer & Saenz, 2003; Neufeld et al., 2001; Parette & Petch-Hogan, 2000), we relied on trusted members of the community and community agencies to gain access to families. Through internet searches and suggestions from community stakeholders, 132 potential recruitment partners in Hamilton and the Greater Toronto Area were determined. An initial email was sent to potential recruitment partners that included a brief overview of the study and a request that they distribute survey information to eligible families. Recommendations for alternative recruitment strategies were welcomed and the Project Coordinator's contact information was provided. Organizations and agencies were contacted a second time by phone or email when there was no response to the initial email.

Organizations and agencies represented six different domains: cultural and immigration agencies, organizations providing services for individuals with disabilities, rehabilitation and health organizations, child and family development service organizations, and neighbourhood and community centres providing services for newcomers to Canada. As well, we contacted researchers in related fields to find names of potential organizations to assist with recruitment.

Cultural and immigration agencies included centres for newcomers, ethno-specific associations, and refugee and recent immigrant service providers. Organizations providing services for individuals with disabilities included parent groups, respite care providers, and disability-specific non-profit organizations (e.g., Spina Bifida & Hydrocephalus Association of Ontario). A small number of organizations delivering services to individuals with disabilities were ethno-specific (e.g., Heep Chi Association in Toronto, the Ethno-Racial People with Disabilities Coalition of Ontario). For rehabilitation and health agencies, we made an effort to reach out to multicultural health centres and urban health centres in diverse neighbourhoods in both Hamilton and Toronto (e.g., Toronto's

Access Alliance Multicultural Health and Community Services, Hamilton's St. Joseph's Immigrant Women's Centre). We also benefited from our affiliation with two major pediatric hospitals. Child and family development service organizations and neighbourhood/community centres included a broad range of service providers; we focused on centres in diverse neighbourhoods and centres that have available services for newcomers to Canada.

We widely distributed information about the survey with the help of 42 community organizations in Toronto and Hamilton (see Table 2). With the help of these recruitment partners, recruitment flyers and survey packages were distributed to eligible families. The recruitment flyer listed the inclusion criteria, allowing parents to self-identify. The flyer provided the web link to the online survey and also indicated that parents could obtain a hard copy of the survey from the recruiting organization (along with a stamped addressed envelope for its return), should they so desire.

Recruitment flyers listed the following inclusion criteria:

- Parent of a child aged 0 to 21 years with a physical disability
- Immigrated from Asia (excluding the Middle East), Africa, or the Caribbean
- Been in Canada for 10 years or less

The study coordinator's contact information was provided for potential questions or paper survey requests. Organizations were encouraged to keep flyers by reception desks and display posters in lobbies and on bulletin boards. Organizations with a client database also mailed out flyers to eligible families or offered survey information during scheduled appointments. In addition, organizations were asked to provide a link to the electronic survey package on their own website whenever possible. Nine organizations posted survey access information on their website and sent survey information through listservs, twitter, and newsletters.

After one month of active recruitment, a new strategy was developed in response to low survey return rates. The research team became concerned that families who struggle with English might be willing to participate but need help to complete the questionnaire booklet. In an attempt to increase participation from families who may like to participate but require some assistance, we offered to cover the cost for an agency staff member to spend the necessary time with a family to help them to complete the questionnaire booklet. Additionally, we offered to cover the cost at local organizations and agencies for an interpreter (if available) to assist interested families in survey completion. All recruitment partners and organizations that did not respond to participation requests were contacted once more to alert them of these methodological changes.

Table 2: Organizations Assisting with Recruitment

Type of Agency/Organization	Number Contacted	Successful Partnerships*			
		Total	Toronto	Hamilton	Ontario
Cultural & Immigration Agencies	49	7	5	1	1
Organizations Providing Services for Individuals with Disabilities	29	8	3	0	5
Rehabilitation & Health Organizations	22	16	9	6	1
Child & Family Development Service Organizations	12	3	2	1	0
Neighbourhood/Community Centres	14	8	6	2	0
Researchers in Related Fields	6	0	0	0	0
TOTAL	132	42	26	10	6

* Successful partnerships were defined as organizations agreeing to assist with recruitment.

Issues Encountered in Recruitment

Despite wide distribution of paper surveys and online link flyers to agencies, only 25 surveys were completed. Issues encountered included unwillingness of community agencies to assist (perhaps due to lack of resources or staff members to assist), language barriers, and a lack of eligible families.

Approximately 41% of the organizations (54/132) did not respond to the initial email or follow-up phone calls and emails. One organization keen on assisting us had staff cut backs early on in the study and could no longer support recruitment. Some staff members who committed to assisting with recruitment were no longer with the agency when we began data collection, and one organization needed compensation in order to justify spending time recruiting.

With respect to language barriers, a number of surveys were returned but left incomplete. Seven surveys were left entirely blank after respondents indicated their eligibility online. In addition, four individuals did not complete the survey section containing the Processes of Care Questionnaire (MPOC-20). Three individuals misunderstood eligibility criteria. One parent completed the survey but their child was over the age of 21, another completed the survey but was originally from Eastern Europe, and the third had a child whose primary diagnosis was Autism. Two organizations enlisted the assistance of professional interpreters to overcome issues with language (St. Joseph's Immigrant Women's Centre, Circle of Friends for Newcomers).

A number of organizations were enthusiastic and appreciated our study's goals; unfortunately, they did not have any families that fit our inclusion criteria. Some organizations had families from the appropriate countries but the children were diagnosed with developmental disabilities (autism, Down syndrome, etc.) rather than physical disabilities. Some organizations served children with

physical disabilities but they were originally from countries that were not included in this study (Israel, Eastern Europe, or the Middle East).

Participants

A total of 15 parents had usable data (11 completed the paper survey and 4 completed the online survey). As shown in Table 3, the typical respondent was a mother 31 years of age. The majority of respondents had a secondary school education or less (9/15) with an income of less than \$29,000. No respondents reported an income above the \$30,000 to \$44,000 income band. They had all been in Canada less than 7 years (thus meeting the eligibility criterion of less than 10 years), with an average length of 5.4 years. The majority were refugees (9/15). Their countries of origin included Burma ($n= 4$), Somalia ($n= 3$), India ($n= 2$), and Angola, Nigeria, and Pakistan (one respondent from each). These numbers are not representative of the immigrant populations in the Greater Toronto Area and Hamilton. We expected there to be a group of families from the Caribbean. Respondents were Black ($n= 5$), South East Asian ($n=5$), or South Asian ($n= 2$). Since many of the families came to Canada as refugees and are low in education and income, these factors need to be taken into account when interpreting the findings.

Their children ranged in age from 2 to 20 years, with a mean age of 7.4 years. Many (13/15) had a diagnosis since birth. Their diagnoses included orthopaedic conditions ($n= 4$), spina bifida ($n= 3$), acquired brain injury ($n= 3$), cerebral palsy ($n= 1$), and amputation ($n= 1$).

Table 3: Participants in the Survey Phase

Characteristic	N or Mean (Range or %)
Parent Characteristics	
Parent Age (years)	30.5 (25 – 50 years)
Female	10 (67%)
Married/Common-Law	14 (93%)
Declined to answer	1 (7%)
Education	
None	1 (6.7%)
Elementary School	7 (46.7%)
Secondary School	1 (6.7%)
College/Vocational School	1 (6.7%)
University Degree	2 (13.3%)
Graduate Degree	2 (13.3%)
Professional Degree	1 (6.7%)
Annual Household Income	
Less than \$15,000	6 (40%)
\$15,000-\$29,000	4 (26.7%)
\$30,000 - \$44,000	2 (13.3%)
Declined to disclose	3 (20%)
Length of Time in Canada (years)	5.36 (1 – 7 years)
Immigration Status	
Family Class	2 (13.3%)
Refugee	9 (60%)
Skilled Worker or Professional	1 (6.7%)
Not reported	3 (20%)
Country of Origin	
Angola	1 (6.7%)
Burma	4 (26.7%)
India	2 (13.3)
Nigeria	1 (6.7%)
Pakistan	1 (6.7%)
Somalia	3 (20%)
Not reported	3 (20%)
Ethnicity	
South Asian	2 (13.3)
Black	5 (33.3)
South East Asian	5 (33.3)
Not reported	3 (20%)
Child Characteristics	
Child Age (years)	7.42 (2 – 20 years)
Child Age at Diagnosis	3.83 (since born – 13)
Primary Disability	
Acquired Brain Injury	3 (20%)
Cerebral Palsy	1 (6.7%)
Spina Bifida/Hydrocephalus	3 (20%)
Orthopedic Condition	4 (26.7%)
Amputation	1 (6.7%)
Not reported	3 (20%)

N = 15.

C. Overview of Data Analyses

Due to low returns, we adopted a descriptive and exploratory approach to the data analysis. First, we calculated descriptive statistics (means, standard deviations, frequencies) for the survey items and scales of the measurement instruments. Second, we determined the extent of unmet needs, with rates over 33% for 'need help or need more help' considered areas of concern (after Schmidt et al., 2007). Third, we examined whether the data supported the following predictions. Based on previous studies and knowledge of the services in Ontario, we had predicted that indicators of a greater level of family integration in Canada (e.g., number of years in Canada, extended family in Canada) would be significant predictors of (a) lower levels of unmet needs, and (b) perceptions of receiving higher levels of family-centred care (Dilworth-Anderson, Williams, & Gibson, 2002; Ho, 2005). Since we did not obtain the desired sample size, the statistical analyses lack power to detect significant differences but were performed for exploratory purposes to detect the presence of trends.

D. Findings

Services Received

As shown in Table 4, doctors were the most common health care provider seen in the last 12 months, followed by physiotherapists and specialists. None of the parents indicated that they saw a Social Worker or Psychologist.

Table 4: Services Received for the Child with a Disability

<i>How many times did your child see this healthcare provider in the last 12 months?</i>	Never	A Few Times	A Lot	Incomplete
Doctor	0	8	5	2
Nurse	5	6	0	4
Occupational Therapist	5	4	2	4
Physiotherapist	3	7	1	4
Psychologist	10	2	0	3
Recreational Therapist	8	2	1	4
Rehabilitation Engineer	8	2	1	4
Service Coordinator	9	0	1	5
Social Worker	7	4	0	4
Specialist	4	6	2	3
Speech Therapist	8	2	1	4

Satisfaction with Services

As shown in Table 5, parents reported that they were generally satisfied with the services they received for their child.

Table 5: Service Satisfaction*

Item	Mean	SD	Median
Overall, are you satisfied with the support you receive from health care services for your child?	3.00	.41	3.00
Overall, does your child receive the services you think she or he needs?	2.62	.77	3.00
Does your child receive the kind of services that you expected to receive in Canada?	2.77	.73	3.00
Have the health care services received by your child helped you to deal more effectively with his or her needs?	2.85	.69	3.00

*Rated on a scale from 1 to 4, with 1 representing 'no, definitely not' and 4 representing 'yes definitely'

N= 13.

Extent of Positive Interactions with Service Providers

As shown in Table 6, parents indicated that they generally had positive interactions with their children's health care providers.

Table 6: Extent of Positive Interactions with Service Providers*

Item	Mean	SD	Median
Warm and welcoming	3.46	.52	3
Take time to listen	3.31	.86	4
Understand child's needs	3.08	.49	3
Understand needs of a newcomer	3.15	.56	3
Support and encourage you	2.77	.73	3
Respect your views of disability	2.85	.80	3
Respect your ability as a parent	3.00	.74	3
Involve you in the treatment	3.23	.60	3
Information and services fit with your background	2.77	.83	3

*Rated on a scale from 1 to 4, with 1 representing 'no, definitely not' and 4 representing 'yes, definitely'
N= 13.

Challenges or Concerns with Health Care Services

In Table 7, on most questions, lower scores represent greater challenges or concerns. In general, parents were neutral in their responses (a score of 3). Areas of greatest challenge were feeling that health care professionals value different things (M= 2.25) and feeling that the amount of information provided was overwhelming (M= 3.00).

Table 7: Challenges or Concerns*

Item Description (Abbreviated)	Mean	SD
+I know where to go for health care services information	3.15	.69
+ I always understand what HCP tell me	3.00	.82
I often have difficulty having HCP understand me	3.23	.60
+ I feel that HCP appreciate the unique challenges of being a newcomer	2.62	.97
I often feel that HCP aren't interested in helping me or my child	4.31	.86
I often feel looked down on when having trouble communicating	3.92	.76

I often feel the amount of information given to me is overwhelming	3.00	1.00
I often feel awkward because I don't know my rights	3.08	1.12
I often feel HCP value different things than I do	2.25	.87
I often feel pressured to take a more active role in decision making	3.38	.96
I often feel afraid to disagree with HCP	3.38	1.26
I often feel uncomfortable communicating	3.31	1.25
I feel uncomfortable with HCP of the opposite sex	3.62	1.39
I feel that HCP communicate with me less because I am a newcomer	3.31	1.38
I feel that HCP give my child less service because we are newcomers	3.67	1.07

* Rated on a scale from 1 to 5, with 1 representing 'Strongly Agree', 2 representing 'Agree', 3 representing 'Neutral', 4 representing 'Disagree', and 5 representing 'Strongly Disagree'
+ Positively worded item (reverse scored for subsequent analyses)

Note. HCP = Health Care Providers
N = 13.

Indicators of Integration

Table 8 reports the frequencies of response to the indicators of integration. Due to the patterns of response (low numbers in some cells), we focused on two indicators of integration in subsequent analyses: (1) Do you have any extended family in Canada? and (2) When did you immigrate to Canada?

Table 8: Response Frequencies for Indicators of Integration

Indicator	No	Yes
Was your spouse born in Canada? (<i>n</i> = 10)	9	1
Do you have any extended family in Canada? (<i>n</i> = 12)	6	6
Have any of your extended family members lived in Canada for more than 10 years? (<i>n</i> = 10)	9	1
When did you immigrate to Canada? (<i>n</i> = 10)	Less Than 5 Years Ago	More Than 5 Years Ago
	4	6

Table 9 provides the correlations among the indicators of integration, showing that they were not significantly related to one another.

Table 9: Correlations among Integration-Related Variables

	Extended Family in Canada?	Extended Family in Canada More Than 10 Years	Length of Time in Canada? <i>(continuous variable)</i>
Spouse born in Canada? <i>(0=no, 1=yes)</i>	Phi= .27, <i>p</i> <.35	Phi= -.08, <i>p</i> <.76	Point biserial correlation= .06, <i>p</i> <.87
Do you have any extended family in Canada? <i>(0=no, 1=yes)</i>		Phi= .28, <i>p</i> <.30	Point biserial correlation= -.02, <i>p</i> <.96
Extended family members in Canada for more than 10 years? <i>(0=no, 1=yes)</i>			Point biserial correlation= .05, <i>p</i> <.88

Reports of Health Care Experiences

We calculated mean scores on items reflecting (a) service satisfaction, (b) extent of positive interactions with service providers, and (c) extent of challenges or concerns. The following table provides the mean scores (and standard deviations) on these groups of items. We first examined the reliability of the items in each item grouping to determine whether there was justification for grouping the items and reporting mean scores. The Cronbach’s alpha values were acceptable for the service satisfaction and challenges groupings (> .70).

Table 10: Reports of Health Care Experiences

Item Grouping	Cronbach’s Alpha	Mean Score (SD)
Service satisfaction ^a (4 items)	.73	2.81 (.49)
Extent of positive interactions with service providers ^a (9 items)	.59	3.08 (.33)
Extent of challenges or concerns ^b (15 items)	.76	3.28 (.49)

^a Rated on a 4-point scale; 1= no, definitely not, 2= no, not really, 3= yes, generally, 4= yes, definitely

^b Rated on a 5-point scale; 1= strongly agree, 2= agree, 3= neutral, 4= disagree, 5= strongly disagree

Levels of Unmet Needs

Table 11 provides data on rates of unmet need in our small sample, in comparison to a national United Kingdom survey of 1,128 parents of children with severe disabilities (Beresford, 1995). In this UK survey, nine out of 10 parents reported at least one unmet need. Three comparable questions were included in the present survey. As shown in Table 11, the rates of unmet need reported by immigrant families were much higher, particularly with respect to needing help finding available services, advocacy, and day to day support for their child. According to Schmidt (2007), rates of over 33% indicate areas of concern.

Table 11: Rates of Unmet Need in Comparison to Non-Immigrant UK Families of Children with Severe Disabilities

Item	Frequencies of Responses (<i>n</i> = 13)			Data from Beresford (1995)*
	I don't need help with this	Not sure	I need help with this ^a	Need unmet or only partially met
I need someone who will show me which services are available to help me	0	0	13 100%	47%
Need to meet other parents with children with disabilities	0	4	9 69.2%	22%
I need help or support in knowing how to advocate for my child	0	2	11 84.6%	question not included
I need day to day support for my child	1	2	10 76.9%	17%
I need emotional support	2	2	9 69.2%	question not included

^a Indicates a response of unmet need

*Data from a survey of parents of children with severe disabilities in the U.K. that used 3 comparable questions; Beresford, B. (1995). *Expert opinions: A national survey of parents caring for a severely disabled child*. Bristol: The Policy Press.

Perceptions of Family-Centred Care

We compared mean scores on the measure of family-centred care (MPOC-20) with data from Ontario-wide samples of English-speaking families of children with disabilities (King et al., 2004) to determine similarities and differences. MPOC-20 assesses perceptions of coordinated and comprehensive care, which may be particularly relevant to the experiences of immigrant parents and the development of rapport needed to facilitate the exchange of accurate information between the parent and service provider (Penner et al., 2007).

Table 12 provides MPOC-20 data for the sample in comparison to an Ontario-wide sample. The means for the immigrant parents are all lower, indicating lower levels of perceived family-centred care, particularly with respect to Enabling and Partnership, and Coordinated and Comprehensive Care, as expected.

Table 12: Family-Centred Care: Comparison with an Ontario-Wide Sample

MPOC-20 Scale	Mean (Standard Deviation)		
	Study Sample ^a	Ontario Sample ^b	T-test
Enabling and Partnership	3.74 (1.49)	5.10 (1.55)	$t(503) = 2.88$ $p < .001$
Providing General Information	3.56 (1.46)	4.09 (1.77)	$t(503) = 0.99$ n.s
Providing Specific Information	4.42 (2.10)	5.23 (1.48)	$t(503) = 1.78$ $p < .10$
Coordinated and Comprehensive Care	3.69 (1.82)	5.25 (1.39)	$t(503) = 3.66$ $p < .001$
Respectful and Supportive Care	4.63 (1.37)	5.40 (1.29)	$t(503) = 1.96$ $p < .10$

Note. Comparison data are from: King, S., King, G., & Rosenbaum, P. (2004). Evaluating health service delivery to children with chronic conditions and their families: Development of a refined Measure of Processes of Care (MPOC-20). *Children's Health Care*, 33(1), 35-57.

^a $N = 11$. ^b $N = 494$.

Exploratory Analyses Involving Integration-Related Variables and Unmet Needs

Since comparative studies are rare (King et al., in press), we took the opportunity to examine associations between integration-related variables and indicators of unmet need. Table 13 provides the intriguing suggestion that parents who do not have extended family in Canada have greater levels of need for emotional support.

Table 13: Extended Family in Canada and Unmet Needs

Unmet Needs Items		Extended Family in Canada?		
		No (n= 6)	Yes (n= 6)	Chi-square
Need someone to show me available services	Don't Need Help	0	0	n.s.
	Not Sure	0	0	
	Need Help	6	6	
Need to meet other parents of children with disabilities	Don't Need Help	0	0	n.s.
	Not Sure	2	1	
	Need Help	4	5	
Need help or support in knowing how to advocate for my child	Don't Need Help	0	0	n.s.
	Not Sure	0	2	
	Need Help	6	4	
Need day to day support for my child	Don't Need Help	1	0	n.s.
	Not Sure	1	0	
	Need Help	4	6	
Need emotional support	Don't Need Help	0	2	$\chi^2(2) = 5.5, p < .06$
	Not Sure	2	0	
	Need Help	4	4	

Table 14 indicates that less recent newcomers were *more likely* to indicate needing help than more recent newcomers, although these trends were not significant. It may be that newly immigrated families have lower expectations for services and are grateful for what they do receive, due to their experiences with services in their countries of origin. Over time, their expectations may rise or they may become more aware of differences in the services they receive in comparison to non-immigrants (Reitz & Banerjee, 2007).

Table 14: Length of Time in Canada and Unmet Needs

Unmet Needs Items		Length of Time in Canada		
		Recent (2006-11) (n= 5)	Less Recent (2000-05) (n= 6)	Chi-square
Need someone to show me available services	Don't Need Help	0	0	n.s.
	Not Sure	0	0	
	Need Help	5	6	
Need to meet other parents of children with disabilities	Don't Need Help	0	0	n.s.
	Not Sure	2	1	
	Need Help	3	5	
Need help or support in knowing how to advocate for my child	Don't Need Help	0	0	$\chi^2(1)= 3.7, p<.18$
	Not Sure	2	0	
	Need Help	3	6	
Need day to day support for my child	Don't Need Help	1	0	$\chi^2(2)= 3.7, p<.16$
	Not Sure	1	0	
	Need Help	3	6	
Need emotional support	Don't Need Help	2	0	$\chi^2(2)= 4.0, p<.14$
	Not Sure	1	1	
	Need Help	2	5	

Exploratory Analyses Involving Integration-Related Variables and Family-Centred Care

Table 15 presents mean scores on the MPOC-20 scales for parents with and without extended family in Canada. This table indicates that immigrant parents who had extended family in Canada felt that they received less general information about the nature of disabilities and services, but more specific information about their child, than did parents who did not have any extended family members. These differences were not statistically significant.

Table 15: Extended Family in Canada and Perceptions of Family-Centred Care

MPOC-20 Scale*	Means (Standard Deviations)			Analyses of Variance
	No Extended Family in Canada (n= 5)	Extended Family in Canada (n= 5)	Total (n= 10)	
Enabling and Partnership	3.57 (2.12)	3.73 (.89)	3.65 (1.54)	$F(1,8)= .03, n.s.$
Providing General Information	3.60 (1.99)	3.16 (.55)	3.38 (1.40)	$F(1,8)= .23, n.s.$

Providing Specific Information	4.00 (2.66)	4.87 (1.86)	4.43 (2.21)	$F(1,8) = .36, n.s.$
Coordinated & Comprehensive Care	3.52 (2.44)	3.55 (1.28)	3.53 (1.84)	$F(1,8) = .001, n.s.$
Respectful & Supportive Care ^a	4.66 (1.92)	4.45 (.79)	4.57 (1.44)	$F(1,7) = .04, n.s.$

* All rated on a 7-point scale with all points labelled, ranging from 1 (not at all) to 7 (to a very great extent)

^a N= 9 for Respectful and Supportive Care

Table 16 presents MPOC-20 data as a function of length of time in Canada. The mean differences in this table are marginally significant. Interestingly, they indicate that the more recent immigrant group has more favourable perceptions of family-centred care, which may reflect the fact that, for newcomers, Canadian health care services are appreciably better than what they have received (Klassen et al., 2011). It appears that changes to perceptions may occur over time, with their experiences becoming less family-centred in nature.

Table 16: Length of Time in Canada and Perceptions of Family-Centred Care

MPOC-20 Scale*	Means (Standard Deviations)			Analyses of Variance
	Immigrated 2006-2011 (n= 4)	Immigrated 2000-2005 (n= 6)	Total (n= 10)	
Enabling and Partnership	4.71 (1.58)	2.94 (1.12)	3.65 (1.54)	$F(1,8) = 4.34, p < .07$
Providing General Information	4.40 (1.19)	2.70 (1.14)	3.38 (1.40)	$F(1,8) = 5.19, p < .05$
Providing Specific Information	5.67 (0.72)	3.61 (2.54)	4.43 (2.21)	$F(1,8) = 2.40, p < .16$
Coordinated & Comprehensive Care	4.71 (2.21)	2.75 (1.14)	3.53 (1.84)	$F(1,8) = 3.48, p < .10$
Respectful & Supportive Care ^a	5.57 (1.40)	4.07 (1.28)	4.57 (1.44)	$F(1,7) = 2.60, p < .15$

* All rated on a 7-point scale with all points labelled, ranging from 1 (not at all) to 7 (to a very great extent)

^a N= 9 for Respectful and Supportive Care

DIRECTIONS FOR FUTURE RESEARCH

- A full scale qualitative study with immigrant parents of children with disabilities would be an important next step, to obtain detailed information about their experiences as caregivers, and their experiences with accessing and using services for their child. Qualitative research is much easier to conduct with immigrant populations than is quantitative research and provides rich descriptive information. However, such research is more limited in its ability to make comparisons and draw conclusions on specific variables, such as extent of unmet need or perceptions of family-centred service.
- There needs to be more quantitative research that focuses on immigrant families raising children with disabilities, to examine their perceptions of culturally sensitive and/or family-centred services, as well as the extent of their unmet needs. This research could focus on different geographical areas, including rural and northern Ontario.
- Research that compares the services and supports of non-immigrant and immigrant families would allow for an understanding of the gaps that exist for immigrant families. In addition, a comparison of recent newcomers' and less recent newcomers' perceptions of family-centred care would provide insight into the reasons why more recent newcomers have more positive perceptions of family-centred care.
- Since recruitment issues were experienced, we recommend that future research take into account the time needed to find and develop access to relevant participants, through the development of relationships and establishing trust with community organizations and immigrant parents. More effective systems for participant recruitment include the use of snowball sampling, and offering incentives to parents to reimburse them for their time. Other methodological recommendations include the need to pay community organizations for assistance with recruitment; the need to employ research assistants with appropriate cultural

backgrounds, specifically with ability to communicate in languages other than English; and the need to develop translated versions of questionnaires to ensure the collection of valid information. These changes would require larger grant budgets.

- A limitation of the present research is that we only included English speaking parents. We suggest that future research expand to understanding the concerns of parents who do not speak English.
- The use of translators and language services is important for immigrant families, as shown in the present research. A useful future direction would be to examine the importance of translation in health care settings, including differences in using professional or family translators.

PHASE 3: KNOWLEDGE DISSEMINATION

Our knowledge dissemination activities will emphasize community engagement, policy recommendations, and future research directions. Stakeholders will be targeted in various ways.

Academic Community

A major means of disseminating the research results will be presentations at key professional conferences, including the 2012 Metropolis conference. Two articles are planned on the findings: one on the qualitative data from Phase 1, and a second article on the methodological challenges we encountered in Phase 2. The second article will be designed to assist those planning quantitative research with immigrant parents of children with disabilities. Findings will be submitted to academic journals such as: *International Journal of Disability, Development and Education*; *Children's Health Care*; *Qualitative Health Research*; *Health and Social Care in the Community*; *Journal on Immigrant Health*; *Disability and Rehabilitation*; and *Disability & Society*. To date, a summary of the research has been included in the Welcoming Communities e-Bulletin.

Government, Community, and Service Providers

Various government ministries such as Citizenship and Immigration Canada, Children and Youth Services, and Community and Social Services will be interested in the research findings. Findings will be disseminated to parents, service providers, and policy decision makers through newsletters, guest talks, grey literature publications, websites, and community forums. To date, a presentation has been made to the Welcoming Communities Initiative. Presentations will be made to staff and families at Holland Bloorview Kids Rehabilitation Hospital and McMaster Children's Hospital. We will share a summary of the qualitative findings and the final report to organizations assisting with recruitment who are interested in learning about the findings.

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