

Barriers and facilitators to health and social service access and utilization for immigrant parents raising a child with a physical disability

Melissa Fellin, Gillian King, Victoria Esses, Sally Lindsay and Anne Klassen

Dr Melissa Fellin is a Post-Doctoral Fellow and Dr Victoria Esses is a Professor, both are based at The University of Western Ontario, London, Canada.

Dr Gillian King is a Senior Scientist and Dr Sally Lindsay is a Scientist, both are based at Holland Bloorview Kids Rehabilitation Hospital, Toronto, Canada.

Dr Anne Klassen is an Associate Professor, based at McMaster University, Hamilton, Canada.

Abstract

Purpose – *The purpose of this paper is to examine the barriers and facilitators to health and social service access and utilization for immigrant parents raising a child with a physical disability, in order to understand their specific needs and experiences of care.*

Design/methodology/approach – *The research involves qualitative interviews with five immigrant parents of four children with a physical disability in two cities in Ontario, Canada.*

Findings – *The findings indicate that divergent perceptions of health care and disability, language, knowledge of service systems, and finances may create obstacles to family-centered and culturally sensitive care. Formal supports, including a third person to navigate the system and services provided in families' homes, are facilitators that enhance the service care experiences of parents.*

Practical implications – *Service providers need to accommodate and work with immigrant parents who have a child with a disability to overcome the barriers to their care. To enhance service experiences formal support and home services should be provided when possible.*

Originality/value – *There is little research on immigrant families' experiences with pediatric rehabilitation services and this study contributes to this area. This paper shows that immigrant families of children with disabilities have barriers to service access, utilization, and service care experiences that are similar to those of non-immigrant families. There are few studies on facilitators to service access and utilization and positive experiences; therefore, this study makes a contribution to this area.*

Keywords *Health, Immigration, Disability, Culturally sensitive care, Family-centred care, Social services*

Paper type *Research paper*

Introduction

Research has shown that there is a lack of knowledge of the specific needs and experiences of immigrant families raising a child with a disability (King *et al.*, 2013), even though many studies show that access and utilization of health care is affected by socio-cultural factors (Newacheck *et al.*, 1993). According to the 2006 Canadian census, the proportion of the population born outside of the country is 19.8 percent (Statistics Canada 2010a) in addition 3.7 percent (202,350) of all children in Canada under the age of 14 reported having a disability (Statistics Canada, 2010b). As a consequence, 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. Immigrants and refugees experience complex issues affecting their access to and utilization of services, as well as their experiences of care (Rhoades *et al.*, 2004). Similarly, the literature on childhood disability indicates that children with disabilities experience a high number of unmet needs and significant barriers to obtaining health care (Mayer *et al.*, 2004).

This study was funded by Citizenship and Immigration Canada. The authors thank Suzanne Robinson and Cortleigh Teolis for their valuable contributions to the project. They thank the families that participated in the study.

Limited data are available to researchers and practitioners to ensure that appropriate services are provided for children from diverse cultures, and to understand the ways that the disability affects children with diverse backgrounds and their families (Dyches *et al.*, 2004).

This study is based on a critical review of the literature on immigrant and refugee families raising a child with a disability, which revealed how little is known about the health and social service access, utilization, and service care experiences of these families accessing and utilizing these services (King *et al.*, 2013). The lack of knowledge of the ways disability is understood and managed across different immigrant groups creates barriers for service providers who are encountering families from a variety of cultures in their practices (Welterlin and LaRue, 2007) and for immigrant families accessing and utilizing services (Skirinda, 2008; Welterlin and LaRue, 2007).

Some research considers the use of culturally sensitive care and how it enhances positive experiences of immigrant families. These positive experiences often include parents' access to resources and experiences with health care professionals who are sensitive to the beliefs, values, and worldviews of the families (Albright, 1997). Culturally sensitive care reflects an eco-cultural approach to treatment planning. The eco-cultural approach considers the family's social and physical environments, including socio-economic factors, the supports available to the family and child, and includes the family's cultural values and beliefs in the treatment approach. In this way, the family's context and goals are included in treatment planning (Moes and Frea, 2000; Zakirova-Engstrand and Granlund, 2009). The inclusion of the family's context and goals is aligned with the family-centered approach to service delivery, considered best practice in pediatric rehabilitation (Rosenbaum *et al.*, 1998).

In the Canadian health care system, services are delivered to children with physical disabilities in rehabilitation and treatment centers that serve specific geographical areas and are also supplemented by provincially funded services and supports through community-based agencies. As such, we also conducted parallel work with service providers' experiences of providing culturally sensitive care to immigrant parents raising a child with a disability (Lindsay *et al.*, 2012), which found that health care and community service providers face many challenges to providing care to immigrant families, including lack of training in culturally sensitive care, language issues, divergent perspectives of healthcare providers and immigrant parents regarding disability, the importance of developing client and service provider relationships, and the need for service providers to help parents to advocate for themselves and their children.

Methods

Design and recruitment

The study's inclusion criteria were first-generation immigrant families to Canada from Asia, Africa, and the Caribbean, living in the Hamilton and Toronto areas. These groups were chosen because between 2001 and 2006 the largest number of immigrants came from these regions (Statistics Canada, 2010a). The participants had to be living in Canada between one and ten consecutive years to be considered "newcomers" (Lo *et al.*, 2010) because many studies show that the settlement process is taking much longer than the five years previously reported (Picot, 2008). In addition, this ensured that parents were in the country for a longer period of time such that they would have some familiarity with the healthcare system and be able to talk meaningfully about barriers and supportive factors they had encountered. Parents had to be able to speak English due to financial constraints of hiring interpreters. The parent's child had to have a physical disability, which included 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.

Ethics approvals for the project were obtained from McMaster University, Hamilton Health Sciences, and Bloorview Research Institute's Research Ethics Boards. Parents were recruited by an introductory e-mail and information package sent to key informants by the Project Coordinator with the assistance of service providers in the two cities, in accordance with strict ethical guidelines regarding initial contact.

Data gathering

Semi-structured interviews were conducted between June and July 2010 with five immigrant parents of four children with a physical disability. The parents' countries of origin were East India, China, Kenya/Somalia, and Haiti. Although the sample size is small, the study provides a focussed initial examination of the health and social service access, utilization and experiences of immigrant parents raising a child with a physical disability. The study builds on our parallel study with service providers (Lindsay *et al.*, 2012) and provides useful information for further research. We encountered difficulties in identifying participants who met the inclusion criteria, as there was a lack of appropriate access points and organizational settings through which to recruit this unique group of parents. We involved 42 community organizations to help with recruitment; however, information regarding immigrant families who have a child with a disability is not tracked which led to low estimates of the number of families who met the inclusion criteria. As well, many of the organizations did not have knowledge of the nature of the children's disabilities that used the services at the organization. As such, the difficulties with recruitment were that there were a small number of parents who met the inclusion criteria and staff not having time to assist in recruitment even though there was an offer to help. Since many other recruitment tools were written (i.e. flyers, information packages) this limited the participation of parents who had difficulty reading English.

For the interviews with immigrant parents of a child with a disability, we obtained an in-depth understanding of parents' experiences, the questions consisted of a series of open-ended questions and more detailed prompts and probes. Topics focussed on parents' experiences in accessing health care for their child, including access to information, medical professionals, medical facilities; their experiences of culturally sensitive and family-centered care; and the nature of their met and unmet needs. The Project Coordinator conducted all interviews, which lasted between 60 and 90 minutes in length and were audio taped for analysis.

Data analysis

A grounded theoretical approach was used to identify categories that emerged in the interviews and to analyze them using literature on theories and practices of culturally sensitive and family-centered care in pediatric rehabilitation (Bernard, 2002). To do this, an experienced transcriptionist transcribed audio recordings verbatim with all identifying information removed. The project drew on interpretive traditions within qualitative research where an in-depth understanding of the participants' experiences is developed (Patton, 1990). All research team members read through each of the transcripts. Three of the authors and a research assistant read through each transcript several times using an open coding approach. The approach allowed for an understanding of the emergent themes and patterns through a close study of the interview transcripts (Bernard, 2002). The two main categories that emerged were barriers and facilitators to access, utilization, and positive experiences of health and social services for immigrant parents raising a child with a physical disability. The major themes that were identified as barriers included divergent perspectives of immigrant parents and health care providers of disabilities and health care systems; language barriers; immigrant parents' knowledge of service systems; financial barriers; experiences of discrimination; and gender relations. The major themes that were identified as facilitators included having a third person to help immigrant parents navigate the system, such as a social worker and health and social service providers visiting the family and treating their child in the family's home. We checked our themes and categories against the literature on immigrant parents raising a child with a disability, culturally sensitive care, and family-centered care. As a result of our analysis, direct quotes from the interviews were abstracted from the transcripts and given a code based on one of the themes listed above (Bernard, 2002). The whole context of the interview was considered when abstracting statements and labeling them with codes (Graneheim and Lundman, 2004). Coding and peer examination of the data analysis helped to ensure the reliability of the findings. The quotes do not reveal the parent or child's gender or any other identifying information to protect the participants' anonymity.

Results

Barriers to health and social services

First, we examine the barriers to health and social service access, utilization and positive experiences for immigrant parents raising a child with a physical disability. In the following section, we show that the parents were often unaware of the extent of the possibilities for independence and the achievement of personal goals for their child with a disability. Furthermore, parents viewed doctors or the medical system as authorities or experts. The other barriers highlighted by the parents included language or access to interpretation services, access to the system, and lack of knowledge of services and funding available. Finally, parents were concerned about experiencing discrimination and receiving culturally sensitive care, specifically surrounding gender relations.

Divergent perspectives of disabilities and health care systems. Families who immigrate to Canada from resource poor countries may not know about the possibilities for a child with a disability, including their independence and their ability to reach their own goals. One parent was grateful and amazed by all the possibilities for his/her child in Canada. When the parent first visited a children's rehabilitation hospital and was given a tour of the facilities he/she was surprised:

[The service provider] showed my [child] a video cassette of what kids like my [child] can do [...] She showed us wheelchair racing, sledge hockey [...] skiing, and everything [...] So [...] it was encouraging to see what a child, like my [child], can do. That there's nothing that they cannot achieve if they put their mind to it (Parent #3).

In the following quote, the same parent discusses the realization of the possibilities for his/her child's increased independence: "We didn't know there were wheelchairs that were so small, but there were wheelchairs for little kids [...] nobody mentioned that, you could take a wheelchair and [my child] could be independent" (Parent #3). Another parent expressed happiness upon realizing the possibilities available to his/her child: "Back in my country [...] kids that have some issue with the physical disabilities, they just sat on the corner [...] things are over for them" (Parent #2). The parents were encouraged about the possible future for their children when they were educated about the nature of his/her child's disability, treatment options, and his/her child's possibilities for independence and his/her ability to reach his/her own goals.

Immigrant families may not be used to a family-centered health care model and conversely see the doctor and medical system as an authority or expert. The result is that families may not discuss their fears with doctors or explore their child's treatment options. One parent agreed to surgery for his/her son even though he/she was uncomfortable with it because of the belief that the doctors are the experts:

[The doctor] came [...] [and did an] x-ray and she said [...] I have to have surgery [on my child] [...] But she said if we don't fix [my child] now, in the future [he/she] would get worst [...] And I believe the doctor can help kids, they don't make them worse, you know? They [are] helping [my child] [...] They have a big diploma and do many tests [...] And I say [...] okay (Parent #2).

Viewing doctors as authorities may lead some families to not discuss their fears with doctors or explore treatment options. One parent admitted to feelings of intimidation from doctors and felt the need to be compliant in order to receive good treatment. One parent suggests that families may not feel comfortable asking for help when they need it: "I do not hesitate to approach people for help. But I know many other families – they hesitate. They are not comfortable approaching people for information" (Parent #3). If parents view doctors as authorities the parent may not be an active participant in their child's health care. As a result, health care providers need to ask specific questions or build relations with parents for them to feel comfortable to raise questions about treatment decisions.

Language barriers. Language was one of the principal barriers to both service access and utilization, even though many health and social service providers have the use of translators or interpretation services. Three of the parents interviewed did not know they had access to a translator and believed they would have made better decisions regarding their child's treatment if they did. One parent admitted he/she only understood about half of the doctor's explanation

about his/her child's diagnosis, "I don't know the language [...] But I'm just keeping saying [...] yes, I understand, maybe most of them, what they say, I don't understand. Yeah, half I understand, half [...] maybe not" (Parent #4). Another parent had similar experiences when his/her child was diagnosed: "If [at] that time would have a [...] translator or interpreter [...] who can communicate with us [...] in our own language, it might be better. There are lots of things we don't understand quite well. We just understand maybe only 10 or 20, 30 percent of [...] what they say" (Parent #1). Language barriers can lead families to make uninformed decisions about treatments. One parent at different times in his/her child's treatment agreed to treatment decisions that he/she was uncomfortable with because he/she could not communicate his/her worry or ask about alternative options: "[My child] had some operation at that time [...] And [my child] got an infection, after the operation, and needed to take some, antibiotics [...] But we don't know how to express our worry, or [...] [ask for] any other options, but we don't know how to say that" (Parent #1).

The parents interviewed found it difficult to understand the specialized medical language used. The parents also highlighted that they did not have previous knowledge of disabilities. Three of the parents articulated these issues in their interviews. One of the parents explains that the cultural meaning behind words and terms can be different. From his/her experience:

When you have a child that has disabilities, or some medical issue. It's really different, there's so much to know, there's so much to learn, and there's so much to understand. From the beginning, what I find was a challenge for me was to understand when the doctor says something to understand, okay well what do you mean, because in my own language it means something else (Parent #2).

Two of the parents expressed that language barriers can lead them to resist treatment recommendations. One parent was resistant to services because he/she did not understand the services being offered. In the following quote he/she discusses respite services, "But the first time, I refuse [...] I just thought [...] I want my child to stay with me" (Parent #4). Another parent was resistant to a doctor's recommendations to contact palliative care when his/her child became very ill because of language barriers, "I didn't know what that means, and I said no [...] I don't want to get in contact with palliative care and stuff like that" (Parent #2). These results suggest that translators and interpretation services should be provided even when English proficiency is assumed.

Service systems. The majority of the interviews with parents pointed to the lack of knowledge among the families of the services available to them. When one parent's child was first diagnosed the parent's concern was, "I didn't even know those things even exist. I thought, okay this is something that I'm going to have to deal with on my own" (Parent #2). One parent explained how he/she would not know the supports that exist if they were not explained to him/her:

Sometimes [my child's] wheelchair breaks and I call the centre and I said, "oh wheelchair light break, or wheelchair seatbelt [...]" Then when they give it to me they left me a business card or some forms and said if something's changed this wheelchair to call us and [...] Of course, if they don't tell me, I wouldn't know, [...] (Parent #4).

The results suggest that service providers can help their clients or patients be aware of the services available to them.

Financial barriers. Families experienced financial barriers that included lack of knowledge of the funding available and the need to pay for equipment before being reimbursed from a funding source. Four of the parents expressed worry over not being able to afford equipment, as one parent articulates, "[My child] needs some [...] special equipment [...] if it's not covered by insurance or [something] [...] we are not going to be able to afford it" (Parent #1). Others may not be able to get or be delayed in getting equipment because they cannot afford to pay for the equipment before being reimbursed. One parent described having to wait for funding to make the house more accessible to his/her child and to get some equipment that the child needs at home: "Especially we are waiting now for [my child's] bathroom [...] we want to do a renovation, and we didn't get the money yet [...] but we will wait" (Parent #4). The results suggest that health care providers can help their clients to become aware of the funding sources available for equipment and services for their children.

Discrimination. Three families discussed fears about the possibility of experiencing discrimination and/or cultural miscommunication. In the following, the parent suggests that there are cultural misunderstandings between service providers and parents:

There could be a misunderstanding, like, you don't know the culture, you don't know the language, and you don't know the customs. So there is hesitancy in both the immigrant part and the native part too, you don't know if what you're doing is right or wrong, so that hesitancy is creating barriers, not discrimination itself as such [...] Familiarity is not there (Parent #3).

Family-centered care includes the respectful treatment of clients or patients and one parent addresses this by expressing worry about whether he/she will be treated differently:

We do have our doubts about how we are going to be treated when we come here [...] So it's there, it's there behind us [...] I know everybody knows I'm a Muslim, how am I going to be treated? It's there at the back of my mind. Are they going to be fair? Will they be as respectful as they would to any other local person? (Parent #3).

The results show that there may be a need for service providers to understand the effects of power imbalances on relations between service providers and immigrant families.

Gender relations. Acceptable gender relations differ across cultures; therefore, culturally normative gender relations are central to culturally sensitive care. Families revealed that gender dynamics play a role in health care use. One parent suggests 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:

Those women mostly who are taking the children to the appointments, but [...] of all [...] the number of families I am coming across [...] they all wait for the husbands to ask the questions, or even for ideas and suggestions to come to them, and then they would be the one to address to the doctors (Parent #3).

The parent suggests that gender relations need to be considered between parents or clients and the service providers:

My [child] [...] [has] been asking for a [same sex] attendant. And the elementary school principal was, I mean, good enough to understand [...] [My child] moved schools [...]. And [my child] is supposed to have a [different sex attendant] and [my child] says – Why? Why should I accept it? (Parent #3).

Appropriate gender relations need to be considered by service providers when working with parents and their children.

Facilitators to health and social services

Along with barriers to health and social services, we examine the facilitators to access, utilization, and positive health and social care experiences for immigrant parents raising a child with a disability. Overall, parents discussed more barriers than facilitators to health and social services; however, we found that families did receive support from service providers. In the following, we show that the parents involved in this study received support when social workers or translators helped them navigate the system. The second factor that facilitated positive experiences was services that were provided in families' homes.

Third person to help navigate the system. All of the parents interviewed suggested that having a third person, such as a social worker, to help them navigate the system increased positive experiences with accessing and utilizing services. Overall, one parent interviewed had very positive experiences and has been able to access services after the doctor recommended a social worker to help the family. The social worker connected the family to a center for children with disabilities and other services: "The social worker finds me up in the community, they have big centre, [...] it's a beautiful place [...] everything is [...] accessible for children [...] she has also connected me to the speech [...] physio" (Parent #4). One parent explains how helpful it was to have a social worker after his/her child was diagnosed, "So from having a social worker [...] wow, okay, this is what's going on, this is what I can get, this is the help that I can get, this is the option, and so on [...] So from there [...] having a social worker was very helpful in getting things done" (Parent #2). Another parent had more negative experiences with accessing

services until recently when the parent got a social worker that speaks the same language as the family does: "The social worker helps a lot [...] with the same language [...] we communicate very well [...] she introduced us to lots of services or something, we can [...] use to help [our child]" (Parent #1).

Home visits. Two of the parents interviewed had positive experiences with services when the services came to their homes and, as a result, believed they were better able to access and utilize services. One parent suggests that she would not have been able access to respite services unless they came to her home, "I don't know how I would find out if they don't tell me what the community has [...] They came to me and give me the idea" (Parent #4). One parent got support from service providers, who come to the family's home:

I get lots of support. Because [...] I got a shift nurse coming in the house four times a week, so that give me time for laundry, cooking [...] [My child] gets some OT (Occupational Therapist) coming in the house to try to walk with [my child] and do some exercise and so on and keeping eyes on things. I pretty much have a really strong team around me (Parent #2).

Two of the parents did not have supports at home and as a result has little time for self-care: "You don't have any leisure time, because [...] [my child] needs 24 hours care, you cannot leave [my child] even two hours, [my child] will be panicked" (Parent #5). The results suggest that a social worker or a third person should be provided to immigrant parents raising a child with a disability to assist them in navigating the system. As well, providing health and social services in the clients' homes would be beneficial in meeting the families' needs.

Discussion

The findings indicate that immigrant parents raising a child with a disability face several barriers to health and social service access and use, some of which are specific to immigrant families and others that parallel research on non-immigrant parents raising a child with a disability. For instance, Beresford (1995) conducted a study that included over 1,000 families of children with disabilities in the UK and found that many families are affected by financial barriers and would benefit from a person to show the families services available as well as a need for holistic and inter-agency approaches to working with families who have a child with a disability. Our research also highlighted positive experiences of health and social service access and use were affected by having a third person to help families. In addition, this study found that positive experiences were associated with service access and utilization when services came to the family's home. As such, our research supports other studies with parents who are raising a child with a disability and report the least well-provided aspect of service is information about the disability and services (King *et al.*, 1998). Furthermore, the present study supports past research that suggests that formal support enhances the service experiences of immigrant families (Hernandez, 2004). The research presented had similar findings with a study focussing on service providers of immigrant families (Lindsay *et al.*, 2012), including barriers around language and communication issues as well as diverse socio-cultural views and beliefs of disability and the need to be sensitive about appropriate gender relations, discussed below.

The research builds upon other studies that suggest that language barriers can lead to lack of knowledge of supports and services (Neufeld *et al.*, 2001), influence decisions about treatment options (Yu *et al.*, 2004), and affect service providers ability to provide family-centered care (Ma, 2000). The parents interviewed were not aware they had access to interpretation services, but believed they would have benefited from the service. The findings show that the lack of access to a translator led some parents to decline services and others to agree to recommendations even though they did not completely understand them. Language barriers also did not allow parents to communicate their concerns about treatments or ask for alternative options.

Other studies have found that poverty, regardless of immigration status, affects access to services and supports for many families raising a child with a disability (Petrenchik, 2008). We found that the families were not aware of the funding available for services or for equipment, unless a social worker or another service provider helped them with the paperwork and to navigate the system. In addition, families did not have the resources to pay for equipment or

other services before being reimbursed by funding agencies. The lack of resources may delay access and utilization of services and equipment that their child needs.

Past research shows immigrant parents' perceptions of disability influences their health care use, which affects families' willingness to seek services and also shapes their views of their child's needs and possibilities (Schuman, 2000). Similarly, we found that parents' past experiences of childhood disability affected their ability to re-imagine the possibilities for their children's increased independence and their child's ability to meet his/her own goals. Our study also found that some parents perceived the health care system and doctors as authorities (see also King *et al.*, 2013), which prevented these parents from asking questions or probing for more information. These divergent perspectives about service provider and client relations also led parents to agree to recommendations they did not fully understand or were not comfortable with, or conversely, they were reluctant to agree to recommendations.

Similar to our parallel study with service providers (Lindsay *et al.*, 2012), the present research demonstrates that gender dynamics need to be considered when working with a family. Gender-related issues include expectations regarding who are the decision makers and the primary caregivers, negotiating roles based on these cultural expectations, and parent preferences for matching the gender of the child and the service provider.

Limitations and future research

The study was conducted as part of a larger research project that aimed to examine the experiences of health and social service access and utilization as well as positive and negative experiences of immigrant parents raising a child with a disability. A limitation to this research is that interviews were conducted with five parents – further work is needed with a larger sample of participants; however, a review of literature on immigrant and refugee families raising a child with disabling conditions (King *et al.*, 2013) and a number of other studies (Daudji *et al.*, 2011; Su, 2007) have found that small sample sizes are a common issue for this area of research. Nonetheless, qualitative studies do not presuppose to generalize their findings (see King *et al.*, 2013, p. 186). In addition, themes identified are consistent with past research in this area.

This paper makes a contribution to past research by showing that immigrant families have many similar barriers to service access and utilization as well as positive experiences as do non-immigrant families, including lack of knowledge of services available and financial barriers (see Beresford, 1995). Few studies examine positive experiences and facilitators to service access and utilization; this study therefore provides new information above and beyond research investigating barriers to service delivery. As well, there is very little research on immigrant families' experiences with pediatric rehabilitation services.

Based on our study, we recommend several areas for future research. There is a need for research that focusses on specific ethnic communities to make comparisons of immigrant families' service care experiences when raising a child with a disability. 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. 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 (King *et al.*, 2011, 2013). To carry out this research, we suggest conducting preliminary research to refine the inclusion criteria for a study with immigrant families and to build relations with community organizations and families to help with increasing participation in the study. A further limitation is that our participants were able to speak English and as a result did not include individuals who may have the most difficulties in accessing and utilizing services. Even the parents in this study, however, would have used interpretation services to ensure that they completely understood what was being said to them. Inclusion of non-English speaking parents is an important consideration for future research.

Conclusions

Health and social service providers need to accommodate and work with immigrant parents who have a child with a disability to overcome the barriers to their care. The research indicated

that language and financial barriers can influence treatment decisions. Furthermore, language and lack of knowledge of the system can be barriers to accessing and utilizing services. Service providers need to be mindful of the role of gender in providing culturally sensitive care. To enhance service experiences, formal supports, such as a third person to navigate the system and home visits, should be provided when possible.

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About the authors

Dr Melissa Fellin is a Post-Doctoral Fellow in the Centre for Research on Migration and Ethnic Relations at The University of Western Ontario. She holds a PhD from the Department of Anthropology and the Collaborative Graduate Program in Migration and Ethnic Relations from The University of Western Ontario in London, Canada. She has extensive experience in ethnographic research and her research interests are in the areas of immigration/migration, refugee studies, children and childhood studies, autism/disability, health and education. Dr Melissa Fellin is the corresponding author and can be contacted at: mstache@uwo.ca

Dr Gillian King is a Senior Scientist at Bloorview Research Institute in Toronto, with appointments at the University of Toronto (physical therapy), Western University (nursing, education,

psychology, family medicine), and McMaster University (rehabilitation sciences). Her primary interest is in the psychosocial aspects of pediatric services and child, youth, and parent well-being. Her research interests include the participation and social inclusion of children/youth with disabilities, youth transitions, parents' wellness and resilience, client engagement, and the experiences of immigrant families raising children with disabling conditions.

Dr Victoria Esses (PhD, University of Toronto) is a Professor of Psychology and Director of the Centre for Research on Migration and Ethnic Relations at the University of Western Ontario. She is also a Principal Investigator of the Pathways to Prosperity Partnership, an alliance of university, community and government partners dedicated to fostering welcoming communities and promoting the integration of migrants and minorities across Canada.

Dr Sally Lindsay, (PhD, Sociology) is a Scientist at the Bloorview Research Institute, Holland Bloorview Kids Rehabilitation Hospital and an Assistant Professor (status) in the Department of Occupational Science and Occupational Therapy at the University of Toronto. Her research focusses on the participation and inclusion of children and youth with disabilities.

Dr Anne Klassen holds a DPhil from the University of Oxford and now an Associate Professor in the Department of Pediatrics and an Associate Member in the Department of Clinical Epidemiology and Biostatistics at the McMaster University. She currently holds a CIHR Mid-Career Award in women's health for her research to understand the experiences of caregivers (single parents; immigrant parents) of parents of children with chronic disease.

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