



Barriers to Health Service Utilization by Immigrant Families Raising a Child with a Disability

Unmet Needs and the Role of Discrimination

Investigators



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Funded by/ Financé par:



Citizenship and
Immigration Canada

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Immigration Canada

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Project Overview

- This **two-phase project** will assess attitudinal, policy, and practice **barriers to health service utilization** by **immigrant families raising a child with a physical disability**
- This is a significant issue with **implications for policy and practice** regarding the integration and well-being of newcomers and their children in Canadian society
- The project involves families from **Asia, Africa, and the Caribbean** living in the **Toronto and Hamilton** areas who have a child with a **physical disability**

Rationale

- Based on a **critical review of the literature** on immigrant/ refugee families raising a child with a disability (King, Esses, & Solomon, in press)
- Little is known about the **health and social service access, utilization, and service care experiences** of these families, particularly in the Canadian context
- Directions identified for research included the need for **comparative studies involving different immigrant populations**
 - This will allow us to determine common and unique barriers and areas of unmet need related to ethnicity

Populations of Interest

- First generation families who have immigrated to Canada within the past 1-10 years from Asia, Africa, or the Caribbean
- Able to communicate in English or French
- Raising a child with a chronic condition associated with **physical functional limitations**, such as cerebral palsy, spina bifida, or a non-progressive muscular disorder



Two Geographical Locations

- We have chosen to focus on families accessing services for their child in two distinct 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: Qualitative Study

- Initial qualitative phase to obtain information about:
 - **Service-related issues** (service access, utilization, and service care experiences)
 - Perceptions of **culturally sensitive and family-centred care** (i.e., individualized and respectful care)
 - **Helpful practices** and ways in which health service organizations respond to the needs of various populations

Phase 1 Methods

- **Four focus groups** (2 in each location)
 - **Community service organization representatives** who provide support to newcomers
 - **Service providers** employed by health care centres
 - 6 to 8 participants per group
- **Six individual interviews** with **immigrant parents** raising a child with **spina bifida or cerebral palsy** (two of the most common chronic disabling conditions in childhood)
 - One parent in each location from each of the 3 populations of interest

Phase 1 Analysis

- Qualitative analysis of themes
- Information will be used to refine the measures to be used in Phase 2



Phase 2: Quantitative Study

- Survey samples of immigrant families from Asia, Africa, and the Caribbean raising a child with a physical disability
- Parents' perceptions regarding health service experiences for their child that are relevant to the issue of discrimination:
 - **Barriers in access** to services
 - **Unmet needs**
 - Extent to which services are **culturally sensitive and family-centred**

Phase 2 Methods

- **Survey package** (English and French versions):
 - Background information survey
 - **Survey of Immigrant Families' Needs and Experiences Regarding Health Services**
 - *Developed for this study*
 - *Domains → Services Received, Service Satisfaction, Interactions with Service Providers, Needs of Child and Family*
 - **Measure of Processes of Care** (MPOC-20)
 - *A psychometrically sound measure of family-centred care, translated into over 12 languages and used worldwide (King, Rosenbaum, & King, 2004)*

Phase 2 Methods

- Aim to obtain **90 competed surveys** (30 from each group)
- Based on an anticipated 40% response rate, we will do an **initial mailing to 225 families** meeting the study criteria:
 - Asian, African, and Caribbean families of a child aged 0 to 21 years with a physical disability who have been in Canada for 1-10 years
- Use of the **Dillman Survey Design Method** to increase response rate
 - Postcard reminders and follow-up mailings to non-responders

Phase 2 Data Analyses

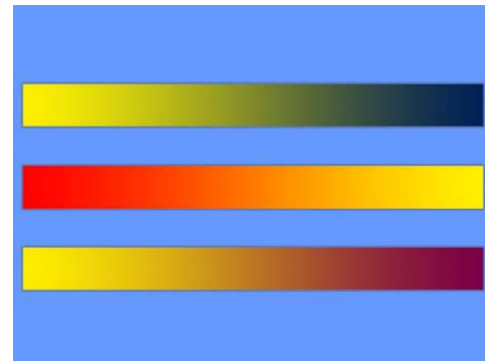
- Descriptive analyses to ascertain **actual experiences and needs**
- Analyses will determine **commonalities and differences in the experiences of the three groups of immigrant families**
 - Along with the qualitative data, this will inform us about attitudinal barriers and discriminatory practices and policies
- Comparisons will be made with **MPOC-20 data** reported in past studies with English-speaking parents of children with physical disabilities (King et al., 1998; King, King, & Rosenbaum, 2004)
 - Enabling and Partnership, Providing General Information, Providing Specific Information about the Child, Coordinated and Comprehensive Care, Respectful and Supportive Care

Timeline

Phases and Tasks	Mar to May 2010	June to July 2010	Aug to Sept 2010	Oct to Nov 2010	Dec to Jan 2011	Feb to Mar 2011
Phase 1: Qualitative Phase						
Ethics approvals						
Development of forms & materials						
Recruitment & partnership development						
Focus groups & interviews						
Transcription & analysis						
Phase 2: Survey						
Refinement & translation of survey package						
Mailings to families						
Data analysis & reports						

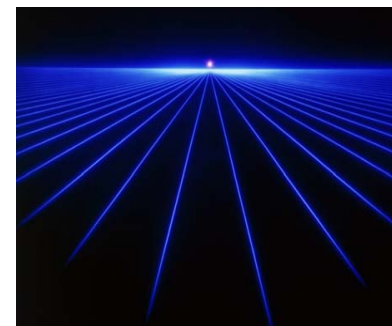
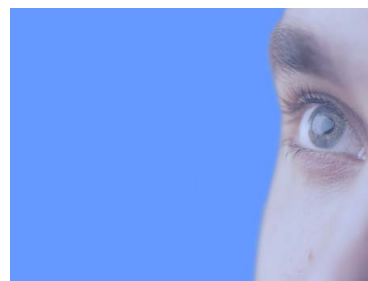
Achievements to Date

- Development of partnering relationships with health care and community organizations
- Development of study measures and recruitment materials
- Ethics approval at Bloorview Research Institute and McMaster University
- Data transfer agreement
- Beginning recruitment for Phase 1 focus groups and interviews



What We Hope to Achieve: Outputs

- Final report to partner organizations
- Presentation to staff and families at Bloorview Kids Rehab
- Presentation to staff and families at McMaster Children's Hospital
- Academic publications
- Conference presentations
- Recommendations for future research



What We Hope to Achieve: Outcomes

Increasing Awareness

- Data on **unmet needs** and perceptions of **discriminatory practices** to guide policy and future research directions
- Increased awareness of the role of the **unique needs and challenges** of immigrant families raising a disabled child
- Increased awareness of the **agency and strength of immigrant families** raising a child with a disability
- Promotion of **public discussion** and awareness of issues and opportunities

What We Hope to Achieve: Outcomes

Increasing Capacity

- Increased capacity of **service providers** to provide culturally competent health care services
- **Effective partnerships** to develop and implement strategies to counter discriminatory behaviors and practice

Changing Behavior & Improving Practice

- **Improved health care utilization** and **reduced discrimination** for immigrant families raising a child with a disability

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