

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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# 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 completed 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
<b>Phase 1: Qualitative Phase</b>						
Ethics approvals						
Development of forms & materials						
Recruitment & partnership development						
Focus groups & interviews						
Transcription & analysis						
<b>Phase 2: Survey</b>						
Refinement & translation of survey package						
Mailings to families						
Data analysis & reports						

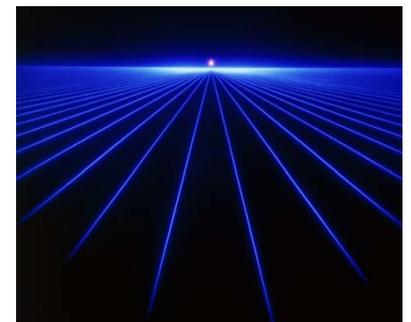
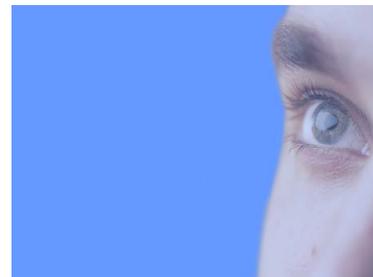
# Achievements to Date

- 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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