

Voices of Immigrant Mothers of Children with Disabilities: Availability and Use of Social Support

WHY IS THIS RESEARCH IMPORTANT?

In Canada more than 202,000 children under age 15 (that's 3.7%) have one or more disabilities. Approximately 96% of the care for these children is provided by their mothers. Research consistently shows that mothers of children with disabilities are twice as likely to report being in "poor" or "fair" health. However, less attention has been given to social supports needed to address the challenges faced by the moms. Current programs and services are missing a key ingredient: the perspectives based on lived experiences of mothers who need to negotiate across multiple sectors to attain required services for their children with disabilities. Even less is known about immigrant mothers of children with disabilities whose experiences as immigrants add to the complexity of the questions being asked. In order to fill this gap in knowledge the Mothers Project was conducted.

The Mothers Project aims to:

1. Understand the perceptions of social support among immigrant mothers of



children with disabilities, and

2. To inform services and social support for mothers of children with disabilities.

DISABILITY and HUMAN RIGHTS

Disability is increasingly being recognized as a human rights issue and is influenced by the un/availability of adequate environmental support for individuals and their families.

Existing services can be strengthened by building greater public awareness, implementing appropriate legislations, and making appropriate policy changes. Doing so will provide more accessible health, rehabilitation, education, social support, and services to immigrant mothers who have children with disabilities.

HOW WAS INFORMATION COLLECTED?

Semi-structured in-depth telephone interviews were conducted with 30 immigrant mothers of children with disabilities and 27 services providers mostly from the Greater Toronto Area.

House's classification of the four domains of social support (structural, instrumental, emotional, and perceptive) was used to analyze, understand and identify the gaps between the needs of mothers and the availability of services at macro, meso, and micro systems levels.

MAIN FINDINGS

POSITIVE EXPERIENCES

Mothers consistently spoke about the ease when information and services were coordinated and available under the same roof. One mother expressed her satisfaction of the services she received in the following words:

The best service was ... It is a wonderful place...lot of help from them....they offered speech, occupational therapy, psychologist services ... they helped on the issue of diet of [my] child with autism and with alternative therapies ...you want to see the result Lots of people are unable to afford counseling as it is very expensive...parents need counseling, they go through lots of stress, and denial. (Mother 5)

BARRIERS TO SERVICES

Availability and Accessibility of Services

...But the multitude of agencies, services scattered all over the place. There are so many. It took so much time, so much energy, so many services, faxes of diagnoses all over the place. So much ...Just one agency to provide proper support to us. Every one gives you a support booklet and you start digging when you should be taking care of the children. (Mother 25)

Participants expressed multiple challenges and barriers in accessing services for their children with disabilities. Both mothers and service providers underscored the issues of:

- disjoint and dispersed services
- language barriers
- discrimination and isolation
- limited/inadequate knowledge of providers
- limited information available regarding services
- long waiting times
- bureaucracy
- limited financial resources

Transportation and Dispersed Services

Most mothers identified the dispersed locations of service providing agencies as a

barrier to accessing services for their children with disabilities. For many newcomer immigrant mothers transportation was a major concern.

...No school busing for the special school. I have to pay for transportation. I have to hire a lady - \$30 a day to take my kids to school... No busing for special school and we really need support in transportation. (Mother 23)

Isolation and Discrimination

Many mothers talked about isolation and loneliness. They felt a lack of emotional support because of the absence of extended family and loss of social networks. Some mothers were concerned by the negative attitudes and discriminatory remarks made by some service providers, especially in school settings.

The schools are reluctant to ... support - a lot of kids have problems and are put into the lowest class with a developmentally delayed program...it is like daycare...Here if you are immigrant and black it is hard to get things done. There are racial inequalities; it is harder for black, Indian, Chinese. You have to play the game...Kids with autism like to touch things and the school put in the addition to his IEP "inappropriate touching"....This was offensive. (Mother 2)

Financial Barriers and Long Wait Times

Many mothers expressed their inability to withstand the financial costs of many of the tests and services that are not covered by government but are required for proper growth of their children. Mothers also expressed their frustration on long waiting times to receive the services.

It is very expensive to get services... everything requires your time, our money; they take such a long time deciding. I still do not know if we will get it... We have to sit and wait...I want to know what is free? (Mother 7)

HOW CAN INFORMATION FROM MOTHERS PROJECT BE USED?

The findings of the Mothers Project can be used by policy and program planners to improve services in moving towards a coordinated model of service delivery, and developing family-oriented services. The findings may also be helpful to mothers as they advocate for timely access to relevant services for their children throughout their growth and development.

Selected References:

1. Bronfenbrenner, U. (1986). Ecology of the family as a context for Human Development: Research perspectives. *Developmental Psychology*, 22(6), 723-742.
2. Chomik, T. A. (2001). The Population Health Template: Key Elements and Actions That Define A Population Health Approach. 1-39. Retrieved from www.phac-aspc.gc.ca/ph-sp/pdf/discussion-eng.pdf
3. House, J. S. (1981). *Work stress and social support*. MA: Addison-Wesley Reading.
4. Statistics Canada. (2006). Participation and Activity Limitation Survey 2006: Families of Children with Disabilities in Canada. Ottawa: Social and Aboriginal Statistics Division.
5. Statistics Canada. (2008). National Longitudinal Survey of Children and Youth (NLSCY). Retrieved from <http://www23.statcan.gc.ca/imdb/p2SV.pl?Function=getSurvey&SurvId=4450&SurvVer=1&Instald=16044&InstaVer=7&SDDS=4450&lang=en&db=imdb&adm=8&dis=2>
6. WHO. (2011). *World Report on Disability*. Malta: World Health Organization.

ABOUT THE INFORMATION SHEET

This information sheet is a short summary of our recently completed qualitative study. The study explores the challenges and facilitators that immigrant mothers encounter in accessing services for their children with disabilities. By capturing the lived experiences of the mothers and by understanding the perspectives of service providers, we can help inform inclusive and relevant policy and program recommendations. The full report with a complete list of references will be ready for dissemination this summer. If you would like a copy, please email to owhchair@yorku.ca with the subject heading 'Mothers Project Report.'

ECHO CHAIR IN WOMEN'S MENTAL HEALTH RESEARCH

The Office of the Echo Chair in Women's Mental Health Research is part of the Faculty of the Health, School of Nursing at York University. We are interested in studying social factors that affect the mental health and wellbeing of women, youth, and children. To learn more about the activities of the office, please visit www.yorku.ca/nkhanlou

ABOUT THE RESEARCHERS

Dr. Nazilla Khanlou is an Associate Professor at York University and the Principal Investigator of this study. Sheila Jennings is a PhD Candidate in law at York University and coordinator of the Mothers Project. She conducted all the interviews for this project. Other team members include Dr. Nasim Haque, Dr. Deborah Davidson, Dr. Mahdieh Dastjerdi, and Wajma Soroor. For detailed information on the entire team, please visit <http://www.yorku.ca/nkhanlou/community-based-research.html>

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