

Research to Action: Social Support Needs of Immigrant Mothers of Children with Disabilities

Nazilla Khanlou and Nasim Haque

Introduction

Government policy on social support for families of children with disabilities is important for ensuring the well-being of all children in Canada. Although much is known of the bio-medical needs of children with disabilities and the challenges parents, and in particular mothers, face in parenting their children, very little is known of the social support needs of immigrant mothers of children with disabilities. To fill this gap we launched a study (Mothers Project) on immigrant mothers of children with disabilities and service providers who are involved in providing services to this population.

The **purpose** of this research was to understand the social support needs of mothers and the challenges they face in accessing services in their day to day life. We report here on the recommendations arising from the study and aimed at informing policy and strengthening services. Detailed findings and the study's methodology are in our forthcoming report, "Voices of Immigrant Mothers of Children with Disabilities: Availability and Use of Social Support."

Mothers of children with disabilities face greater social support challenges as compared to mothers in the general population. The intersectionality of immigration, settlement and caring for children with disabilities, in a new environment, adds to the complexity of



meeting the support needs of immigrant mothers and their children. Mothers of children with disabilities are disadvantaged in at least four dimensions when accessing health care and other support services: (i) children with disabilities have greater health needs as compared to other children; (ii) children with disabilities experience greater barriers in accessing appropriate health care and other support services; (iii) when services are accessed these children are more likely to receive inadequate care; and (iv) many immigrant mothers have limited knowledge of how services are organized and accessed in Canada and, therefore, have difficulty in navigating the system. In some cases English as a second language may act as an additional barrier for immigrant mothers when accessing services.

Main Findings

The findings from our study draw attention to a wide range of issues immigrant mothers

of children with disabilities face. The findings highlight the inadequacies in the current system in addressing the social support needs of mothers of children with disabilities and their families. Using House's (1981) classification of social support, the facilitators and challenges described by participants were grouped under four domains as illustrated in Box 1. A snapshot of these findings is also available in our Information Sheet #1, "Voices of Immigrant Mothers of Children with Disabilities: Availability and Use of Social Support" located at www.yorku.ca/nkhanlou

Box 1: Categories of Supports Identified

1. Structural Support

- Family, health, and social services
- Cultural acceptability of social services
- School services

2. Instrumental Support

- Family and friends
- Extended family
- Informal networks

3. Emotional Support

- Spouse/partner

4. Perceptive Support

- Mothers' perception of adequacy of social support

Policy Implications

The wide-ranging nature of challenges referred to by study participants draw attention to the impact that inadequacies in the current support systems have on the lives of mothers with children with disabilities and their families. Presently, services do not adequately fulfill the needs of new immigrant mothers. A key reason for this could be the lack of family-centred and

timely service availability. This in turn may lead to poor access to health care, school services and other required social services, resulting in increased stress and 'extra-ordinary' demands associated with mothering children with disabilities.

..... general lack of understanding of our system. Families were unsure where they can go to access resources and to investigate services. It is very difficult for them to get such information. Many of my clients do not have a caseworker or social worker to work with. What is needed is a central person to whom immigrant families can go to ask what is available. (Service Provider 3)

Main Recommendations

1) Improve access to services - Use best practices to introduce Key Workers or Case Managers in the system.

Many immigrant mothers, due to their limited knowledge of how services are organized and accessed in Canada, and in some cases due to their limited English language skills, may encounter difficulties in: completing extensive paper work, finding out what services are available, overcoming the barriers of transportation, and most importantly knowing who they should consult with if they needed help in a particular area. Perhaps, as suggested by many study participants, a model may be built where a single service provider, such as a key worker or a case manager¹ would

¹ Key worker is the person who coordinates, manages, and has a professional overview of a family's early support needs.

Carter, B. and M. Thomas (2011). *Key Working for Families with Young Disabled Children*. Nurs Research Practice.

work with the mother to find the appropriate information and services and support her with paperwork and act as the family's main point of contact. Mothers require interventions from multiple social services. Lack of inter-agency coordination and fragmentation in services results in confusion and increases the demands upon mothers.

A case management system would be incredibly effective, one which dealt with issues pertaining to schooling, health care, benefits available in the tax system. (Service Provider 1)

2) Ensure adequate resources are provided for effective delivery of services either through government funds or through expansion of health and social insurance policies. However, to ensure equitable access of services, special funding allocations must be in place for disadvantaged and economically poor populations.

Our findings corroborate with previous research and suggest that many of the services did not have adequate resources which resulted in long wait times for the services. Many mothers referred to the high costs of services and how excessive out-of-pocket cost was straining their house-hold budget. They also

Eight months on wait list – so we went with private [speech] therapy – out of pocket in the beginning. \$125 per session. My husband is not making that much money. (Mother 19)

expressed their frustrations of not having access to financial support, and as immigrants they felt they did not have enough financial resources to support their child to the level they would have liked.

3) Improve inter and cross-sectoral service coordination through appropriate legislation.

Mothers of children with disabilities usually require interventions from different services, such as health, education, social services housing, and social benefits agencies. During the course of seeking services for their children, mothers encounter numerous contacts with different workers. In the current system there is lack of co-ordination between the different agencies providing services to children with disabilities. The services are too dispersed and fragmented causing confusion and thus increased demands on mothers.

4) Ensure availability of respite care for mothers of children with disabilities to give them temporary relief and ease the demands of daily care.

Mothers repeatedly referred to having no time to relax or to attend to their own needs. Mothers said they needed help with care and domestic tasks including periodic relief at night.

5) To empower immigrant mothers and to have social support programs informed by their lived experiences, actively involve mothers in the process of planning, program implementation and governance.

Immigrant mothers who are experiencing challenges in accessing the system for their children with disabilities have unique insights

about their situation, of which researchers, policy makers and program planners are not aware. Therefore, in formulating and implementing policies, laws, services, and programs, immigrant mothers of children with disabilities should be consulted and actively involved. This can be done by ensuring appropriate representation and active participation in all phases of education and health services processes as an integral feature of "right to health" and education. The process of inclusion can empower immigrant mothers of children with disabilities and, thereby, help to further reduce health inequities and disparities. To foster active participation, provide participating mothers with the option of

respite or assistance.

How can information from the Mothers Project be used?

The findings of the Mothers Project can be used by policy and program planners to improve social support and 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.

ABOUT THE INFORMATION SHEET

This information sheet is second in this series and provides the key messages from our recently completed qualitative study on immigrant mothers of children with disabilities. 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.

WOMEN'S HEALTH RESEARCH CHAIR IN MENTAL HEALTH

The Office of Women's Health Research Chair in Mental Health 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 was the 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>

FUNDING: Funding for the project was provided by the Faculty of Health, York University.