

Service Providers Views of Social Support and Immigrant Mothers of Children with Disabilities

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Why Service Providers?

Canada attracts more than 200,000 newcomers annually. Immigrants accounted for 20% of Canada's population in 2005, and this proportion is projected to reach between 25% and 28% by 2031 (Statistics Canada, 2010). As the population is becoming more ethnically and culturally diverse, the call on our service delivery systems to provide culturally appropriate services is also increasing. Evidence shows that among poorer and more isolated immigrant women in Toronto as well as newly arrived immigrants, access to health-care services continues to be an important issue. Language barriers and cultural differences often make it difficult for non-French or non-English speaking immigrant mothers to obtain the information needed to make important decisions about health, to navigate the health system and social services, and to access culturally appropriate services.

Similar to language being a challenge for immigrant mothers, it is equally as difficult for service providers to communicate effectively with patients and clients. This communication barrier affects the way they interact with parents. Interpreters are used in some cases; however it continues to be difficult to provide adequate care. Three main issues are highlighted in the literature: lack of specific training, language, and building a trusting bond. Many service providers feel there is a lack of training at the professional level to provide support for minority groups.

Why immigrant mothers of children with disabilities?

Across Canada, 202,350 (3.7%) children under



the age of 15 years and 102,680 (2.5%) of all children between the ages of 15 and 24 years have one or more disabilities. Research consistently shows that mothers of children with disabilities are twice as likely to report being in "poor" or "fair" health. Although, mothers of children with disabilities face greater social support challenges as compared to mothers in the general population, very little is known about what constitutes helpful social support and facilitates access to services for immigrant mothers of children with disabilities.

What we did?

To fill the research gap, in 2012, we launched a qualitative study (Mothers Project) on immigrant mothers of children with disabilities and service providers who are involved in providing services to immigrant mothers of children with disabilities. The purpose of this research was to explore the experiences of immigrant mothers of children with disabilities and to understand the challenges they face in accessing services for their children and themselves. Thirty mothers and 27 service providers participated in this study. This study is unique because it is one of the few studies which integrated service providers' perspectives with the experiential accounts of immigrant mothers of children with

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disabilities.

In this Information Sheet we report on the views of service providers in relation to the barriers faced by culturally diverse immigrant mothers of children with disabilities. For details on the overall findings and the mothers' perspectives, see Information Sheets 1 and 2 available at www.yorku.ca/nkhanlou

What we Found?

Service providers (SP) in this study identified multiple barriers faced by immigrant mothers of children with disabilities and discussed how these barriers prevent or reduce the ability of mothers to access social support and services. For example, at the community level mothers may not have sufficient financial support and at the family level there may be limited support from their partners, family and friends.

The service providers specifically spoke about the barriers present in our current health care, social services and education system and how they hinder immigrant mothers of children with disabilities from accessing the needed services. In this information sheet we present some of the challenges that service providers pointed out.

Navigating Systems

Services providers recognized the difficulties mothers encountered in understanding and navigating multiple systems. They pointed out that language barriers and unfamiliarity with the new systems in a new country were the main hindrances in accessing relevant services.

There is a 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. (SP 3)

Language Barriers

Service providers emphasized that many new immigrant parents speak and understand English

as a second language, which creates difficulty in interacting and understanding health care and social services professionals. This lack of understanding between mothers and service providers can result in misinterpretations of a diagnosis, difficulties in accessing necessary services, and challenges in receiving appropriate treatment and support.

The language issue is huge if the person is not comfortable with English. (SP 13)

Service providers also recognized that medical/clinical language used by them is often complex and mothers may not completely understand the specifics and need clarification.

Families have difficulty with terminology. What is respite for example? Maybe they need respite; maybe they don't need it... They may need help to maneuver through the service delivery system. (SP 20)

Extensive Paper Work to Receive Services

Both mothers and service providers stated that the large amount of paper work was a barrier to accessing services. Service providers noted that mothers would benefit from having someone work with them to help them understand and complete the required forms.

The main difficulty is that forms are very long and complicated.... It is like a full-time job there is so much work to coordinate What the mothers need is someone who will sit down with them and fill out forms for them and provide them with advice. (SP 7)

Dispersed Services

Service providers noted the difficulty mothers have in accessing services which are dispersed through different agencies across the GTA. They recognized that having a centralized case manager would help with the coordination of services for these families.

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. (SP 3)

Lack of Awareness of Client Needs

Service providers recognized that they may have inadequate information regarding the needs of mothers of children with disabilities.

Disability awareness as a whole is a problem. Yes, there is a special needs unit. Some children aid society workers don't know what assistance is available for children with severe disabilities. They need to know more about that whole world. (SP 18)

Stigma/ Cultural Acceptability

Service providers recognized that the cultural beliefs and values of immigrant mothers influence how they define the nature and cause of their child's disability. They reported observing the struggle some mothers face in trying to cope with the feeling of being devalued and stigmatized by society because they gave birth to a child with disability.

The stigma born by a child with disabilities in other cultures and in the dominant culture is a barrier. (SP 2)

Lack of Support from Family and Friends

Service providers noted that immigrant mothers face additional challenges in caring for children with disabilities because their support networks may be small or completely disrupted as a result of immigration. This results in a lack of or smaller social support network which mothers can access for emotional, financial and non-financial support.

It is devastatingly difficult to care for these children. Immigrant mothers are less likely to carpool, less likely to have friends who could pick up groceries for them [and over time because of intense demands] friends fade away. (SP 20)

Conclusion

This study is one of the first to examine immigrant mothers of children with disabilities access to helpful social support in Ontario by examining both the mothers' and service providers' perspectives. The findings indicate that the service provider views mostly echo the voices of the mothers. Further, mothers of children with disabilities have many unmet needs which are associated with gaps in service delivery.

How project information can 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, providing appropriate training

to service providers and developing culturally appropriate, and 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.

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ABOUT THE INFORMATION SHEET

This information sheet is the 3rd in this series and provides the views of service providers regarding the social support challenges faced by immigrant mothers of children with disabilities from our Mothers Project. The study explored the enabling factors and the challenges immigrant mothers encounter in their day to day life in accessing the needed support and 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 effective policy and program recommendations.

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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>

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