



**“PARENTING WITH A DISABILITY: DIVERSITY, BARRIERS
& REQUIREMENTS”**

An Exploratory Research Report

By

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October 31, 2005

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EXECUTIVE SUMMARY

Parents with disabilities from diverse backgrounds, and specifically mothers with disabilities, require accommodations during the early years of child rearing. This exploratory research study portrays individual stories of parents with disabilities from diverse backgrounds and highlights the barriers and requirements given the elements of disability, gender, race, culture, faith, family composition and socio-economic participation. It identifies themes and patterns in the analysis and makes recommendations aimed to better accommodate parents with disabilities. The themes include:

- impact of ethno-cultural and faith backgrounds
- attitude about disability
- access to transportation
- social housing and accessible housing
- nurturing supports
- financial status
- and immigration policies

The report concludes that the fact that a person has a disability and is also a parent has to be considered in the provision of accommodations like special transportation, attendant care and nurturing assistance.

Foreword

I am Rabia S. Khedr, the author of this study. I am a Muslim-Pakistani-Canadian woman with a disability. I am legally or illegally blind. My husband, Hossam Khedr, is a Muslim-Egyptian-Canadian. We have four young, truly Canadian children; three girls and one boy. The eldest, Sumaya, is turning ten. Shayma is turning eight. Yusef, the only boy is six, and the youngest, Ruqaya, is barely three. I am a career woman with my own consulting company. I have finally struck a balance in my life as a wife, mother and career woman primarily by working out of my house and purchasing the supports I require to accommodate me both having a career and family.

However, it was not easy getting by without a paid support system. Although my disability, namely, vision loss, did not require me to have personal care assistance, I certainly required assistance in running an organized household and nurturing my family. I depended on my mother's help in sorting laundry and tidying up. I counted on volunteers for my grocery shopping and homework help for the kids. I found myself at the mercy of people's availability. Grocery shopping was not a task that could be put off for another week with four young children. I felt that my money was far better spent purchasing help that I could direct and manage. My life has never been better.

I got tired of the societal assumption that individuals with disabilities are dependent on the people in their lives, rather than seeing that people depend on them for their lives. I was inspired to change this misperception. I decided to begin by undertaking this exploratory study to tell the stories of individuals with disabilities who also happen to be parents. I was interested in investigating the differences in the support requirements of diverse parents with disabilities who were raising young children from a gender perspective, in terms of family composition, financial capacity, and different disabilities. I hope that the patterns and themes that emerge will result in further research and policy recommendations that will enhance services and supports for parents with disabilities to provide a healthy, structured and balanced environment for nurturing their children.

Acknowledgements

This research study was made possible through a grant from the Canadian Centre on Disability Studies (CCDS).

From the inception of this study, thank you to Dr. Roy Hanes at Carleton University for helping me focus and capture the concept into a concrete proposal.

Thank you to the advisory group comprised of representatives from the Ethno-Racial People with Disabilities Coalition of Ontario (ERDCO) and the Centre for Independent Living in Toronto for helping guide the process and assisting with outreach.

Thank you to the research participants. Without their input and openness to share personal stories, this report would not have been possible.

Thank you to Zubeda Vahed who edited this report for me.

A most gracious and heart-felt thank you to Colleen Watters from CCDS for her patience and willingness to listen to my concerns.

Introduction

People with disabilities are diverse in their individual identities, living environment and life experience as people without disabilities. Their identity, environment and life experience is shaped by the disability experiences and resulting barriers and the skills to overcome the barriers. The disability experience is also individual and diverse. It is determined by the type of disability, the point in time the disability started (whether from birth or later in life) and the socio-economic circumstances of the individual and their family. Nevertheless, parents with disabilities, and specifically mothers with disabilities, require accommodations in order to ensure a well nurturing healthy childhood for their children. The fact that parents have disabilities has to be considered in the provision of accommodations like special transportation, attendant care and nurturing assistance.

This exploratory research study portrays individual stories of parents with disabilities from diverse backgrounds. The individual portraits highlight the barriers and requirements given the elements of disability, gender, race, culture, faith, family composition and socio-economic participation. It identifies themes and patterns in the analysis and makes recommendations aimed to better accommodate parents with disabilities.

An Overview of Parenting with a Disability

Parenting is a challenge regardless of ability. In today's post-industrial, urban and multicultural society, rearing and raising children has become a very challenging process. Children and infants have many social, educational, psychological, physical, recreational and emotional needs. However, because of many factors including the need for dual income parents, the loss of the extended family, as well as the replacement of informal neighbourhood and community activities by formal structures and organizations, children and infants must be enrolled in programs if they are to get many of the above mentioned services. Children need to be nurtured and loved. They also need to be intellectually stimulated, socialized in different environments and have their development monitored. Children in their early years may require regular medical services. They require stimulation through informal educational activities such as reading, colouring and crafts. They require social and recreational activities through informal play, swimming lessons etc. in their early years to ensure healthy development.

In recent years, media reports as well as research on getting and keeping children involved in informal or formal activities indicates there is a great deal of pressure on parents. If the parent or parents are disabled these pressures are significantly greater. These parents and likewise their children face barriers to accessing appropriate supports, services and activities. When we add racial and cultural diversity to the equation, the barriers become greater; hence this author would argue that it is important for us to explore how the barriers faced by ethno-racial minority parents with disabilities are different, if not heightened.

Although there is a great deal of information about parenting children with disabilities and some information about parents who have disabilities, there is no literature profiling intersectionalities of culture, class, faith, gender and parental disability. This research project hopes to address this omission by examining the importance of these "intersectionalities" in the child rearing process.

There are clear differences in parental values toward child rearing given the ethno-racial/ethno-cultural backgrounds of families. Support requirements vary among parents with disabilities, not only among the intersectionalities that make up the identity of parents with disabilities, but also within the requirements of different types of disabilities. It is important that we develop comparative portraits that explore barriers and requirements for formal and informal supports that parents with disabilities need in accessing health services, education, social recreational activities and employment; their ethno-racial/ethno-cultural background; their family structure; their faith and community links as well as their socio-economic status.

If we are to ensure that parents, regardless of race, culture, class and ability have a positive parenting experience and pursue healthy lifestyles for their children's early years, it is important that we understand the support requirements and ensure that social policies and programs reflect these. This qualitative research initiative gathers portraits of parents from different backgrounds with different disabilities, to tell their stories describing their barriers and support requirements, analyze the gaps in supports and makes recommendations for further research in the hope of fostering innovative policy changes.

Methodology

Consumer directed disability groups and service providers agree that there is a gap in knowledge with respect to parents with disabilities from diverse backgrounds and their support requirements. The Centre for Independent Living in Toronto (CILT) has pioneered resources as they relate to parents with physical disabilities. The Ethno Racial People With Disabilities Coalition Of Ontario (ERDCO) has also pioneered research with respect to double and triple disadvantaged individuals and has engaged in informal conversations with parents with disabilities. (Appendix A)

It is commonly stated by parents with disabilities that they have to beg or buy supports. Depending on their ethno racial/ethno cultural backgrounds, some parents with disabilities find themselves depending on their extended family supports. In many circumstances, parents with disabilities may find themselves feeling powerless and compromising their values as parents because they are depending on the generosity of informal support providers.

A collaborative partnership was pursued by the researcher with these two organizations in order to guide the research process through a preliminary advisory meeting. The partners were asked to assist in identifying interview participants and focus group participants. Once the report was drafted, the partners reviewed the report and will assist in the dissemination of the final report.

This project undertook a participatory action research approach to gathering information and used its partners in an advisory capacity as described.

- In the collaborative partnership, guiding principles were developed.
- An outreach notice describing the research and participation sought was circulated in the form of personal emails was sent out to the advisory group members in order to assist in recruiting participants.
- A confidentiality agreement (Appendix B) and an interview questionnaire (Appendix C) were developed to assist in building comparative portraits of parents and was presented to the collaborative partners for feedback.
- Participants with different disabilities were sought who were mothers and fathers of children aged between thirteen and under. These participants represented various intersectionalities of race, culture, disability, gender, faith and familial roles. Participants were either single parents, were parents where one parent had a disability or where both parents had disabilities.
- Eight interviews were conducted in the Greater Toronto Area and transcribed.
- Eight comparative portraits were drafted to describe individual lifestyles, intersectionalities, barriers and requirements.
- Preliminary data was extrapolated and a summary was shared with participants for feedback.
- The data was presented for participatory analysis at a focus group (Appendix D) bringing together interview participants and other key informants as recommended by the collaborative partners (i.e. community advocates who are familiar with the issues, service

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providers who interact with parents with disabilities...) to validate findings, provide additional information and assist in forming recommendations.

- The focus group results were analyzed further and compiled into a draft report. The collaborative partners were asked for feedback. The final report tells real stories (with an omission or modification of any identifying information to reduce the risk that participants would be identified), identifies barriers and requirements given the intersectionalities explored and makes broad recommendations for future work. The report was shared with the participants before the submission.

Report Dissemination:

The report will be available online and will be disseminated electronically to legislative policy makers, social policy researchers and disability rights organizations as well as made available to all the participants.

Description of Interview Participants

Attribute	Description
Gender	<ul style="list-style-type: none"> ➤ 5 females ➤ 3 males
Disability	<ul style="list-style-type: none"> ➤ 2 blind ➤ 1 low vision ➤ 1 low vision/hard of hearing ➤ 1 deaf ➤ 3 mobility
Family	<ul style="list-style-type: none"> ➤ 3 single mothers ➤ 1 deaf couple ➤ 1 blind couple ➤ 1 couple with 1 mobility and 1 mental health disability ➤ 2 couples with fathers with disabilities
Financial status	<ul style="list-style-type: none"> ➤ 3 fixed income ➤ 1 low income ➤ 3 working class ➤ 1 high income
Ethnoracial/ethnocultural background	<ul style="list-style-type: none"> ➤ 3 Caribbean-Canadian ➤ 3 South Asian ➤ 2 Middle Eastern
Faith background	<ul style="list-style-type: none"> ➤ 2 Christian ➤ 2 Hindu ➤ 3 Muslim ➤ 1 Sikh
Immigration status	<ul style="list-style-type: none"> ➤ 8 Naturalized Canadian Citizens

Portraits of Participants

Ms. S.

Ms. S is originally from the Caribbean. Ms. S. is a single mother who is hard of hearing and also has progressive vision loss. She has a twelve year old daughter whom she has been parenting alone for over nine years. Her ex-husband has very limited involvement in their life. Although she has always had hearing loss, the vision loss has become apparent in recent years. It is enough to prevent her from being eligible to drive, and remains an invisible disability, thus often posing a challenge for people to take her seriously and accommodate her appropriately.

As a single mother she faces financial barriers. As a woman who is black and has two sensory disabilities, she faces barriers to employment contributing to her financial hardship.

“I have multiple disabilities. I’m black and I’m a black woman. It’s hard for a woman in the business world; and then to be a black woman in the business world and then a black woman with multiple disabilities, I have these things that, I don’t want to say not going for me, but they present a challenge for me.”

She worked with her current employer for a year and a half before being laid off for the summer. She was recently recalled to her job. Not knowing about future prospects, she spent her entire summer vigorously job searching.

“...the thing about having a disability is that you are not the average person so you cannot be very optimistic when you lose your job. There is always the wall because employers are not very willing a lot of times to give you chances. I don’t get angry about it; it’s hurtful sometimes, but then I understand that people are very ignorant about disabilities, and so they tend to judge your capabilities by the fact that you’re not like them.”

Ms. S. has a busy life. Her community involvements evolve around church activities for her and her daughter. They attend weekly church congregations and often join their church families for luncheons. Her daughter performs with the choir so they are committed to weekly choir practices. She also finds time to volunteer her administrative skills to the cancer society.

She would like to do more with her daughter in terms of leisure activities. Transportation is a significant barrier because she does not drive and financial constraints are an additional barrier. She finds herself always having to arrange so many things by way of transportation in order to participate in her existing community involvements and support her daughter’s social activities. Most activities are held in the evenings. She is concerned about walking and taking the bus late at night, particularly in the winter. She also feels that she is often unable to arrange for her daughter to participate in the usual day trip activities that families enjoy during the summer. She finds it difficult to manage without access to a vehicle or an affordable alternative to take her daughter on picnics or to attractions like Wonderland.

Mrs. J.

Mrs. J and her husband are both blind. They have three children. Mrs. J. is self-employed and works from her home. Her husband holds a good position in the financial sector. They own a house on a quiet urban street just across from an elementary school. Regardless of their financial capacity and supports, parenting is a challenge for them as a couple.

There are clearly defined traditional gender roles within the household regardless of the fact that both parents are blind, but Mrs. J. states that her husband does actively play the parenting role and helps with the children's daily routine. Her husband is the primary breadwinner. She works part-time, from home and she manages the household.

“My husband gives the money but I have to rule the house. My husband also is very helpful in raising the kids. He brushes their teeth and gives them a bath. He's an Asian typical dad, he plays the cultural role. He likes routine; in the morning breakfast is at 6:30 – 7:00 and lunch at 12:00. He supervises but he wants the food on the table.”

Mrs. J. requires supports to provide a healthy and nurturing lifestyle for her kids particularly in the early years. She counts on friends and neighbours to assist her in emergency situations and for very visual tasks. She finds herself helping lots of people, and in turn they are ready to help her.

“In my neighborhood I have a lot of friends and I help a lot of people. They also help me if in any case... especially one time my children got ear infections and things like that, I always get help from my neighbors....I have a problem when they were infants, cutting their nails. I can cut my own but I couldn't with them. I have a lot of friends so I get someone to clip them. I'm in a community where they need a lot of information about all kinds of things like immigration, teaching, tuition and everything. Sometimes, I teach some girls English and even if someone wants to apply for citizenship, I teach them. They like me, plus I'm a very people's person. It's not a problem for me. I always listen to the radio and get information to pass it around. I talk to a lot of people; even I go to the hospital sometimes and stay with people delivering. It's a give and take; you always have to give something so people will be ready to help you. I get help from people in so many ways, like sometimes they go to the store and get things for me, give me some information here and there and help me colour my hair.”

As her children are growing, she is able to rely on the elder child to help with some tasks. However, her husband tells her that he is concerned that if she gets dependent on the kids, they will begin taking advantage of the fact that they have parents with disabilities.

Mrs. J.'s family is very involved in different cultural and community activities. However, transportation is a barrier for her. She is nervous and scared to just trust her hearing when walking to the bus stop or crossing the street.

“We take our kids to community activities. We have 24 hour radios and they always organize get-togethers in the parks and halls - Sri Lankan Community activities. We go to other things like birthday parties and weddings. We're also sending our children to music lessons, religious

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classes and language classes. I don't take them, but my husband does. I have a weakness, mobility, like taking the bus. I'm very scared to go by myself. I'm a little nervous. Earlier, I could see the white line on the road and cross, but now I can't trust my hearing, it's a major problem."

Although she takes her kids to the park, she feels vulnerable outdoors in open environments.

"I always take them to the park beside our house. They are old enough but I'm still scared to take them. I need some help with supervision."

There are things that she needs help with in her regular household routine.

"A home maker comes three days for two hours through VHA (visiting homemakers) it's a Metro service they help with shopping, ironing, matching clothes, shirts and colors, cutting meats, cleaning things we can't see. My brothers also, come on weekends and do some shopping and things."

Mrs. J. feels that the help from friends and family and other coordinated services really assist with the quality of life in her household.

"The volunteer, a retired teacher, and the homemaker assist me in having a healthy relationship with my kids."

Although she is doing a lot of activities with her kids, she still would like to do more things without just depending on friends and volunteers.

Mrs. J. also expresses that their ethno-racial background combined with the fact that both parents are blind, creates a stigma that they are somehow unfit as parents. She states that the local school that her children attend expressed a concern about the children safety. There is a path directly across their house to the school. Her children walk through there like all other kids. However, the school administration were concerned and got Children's Aid involved to consult with the parents to ensure safeguards for the kids.

Mr. K.

Mr. K. is a musician who acquired Multiple Sclerosis (MS) over 20 years ago. When the doctor examined him, the doctor commented that the symptoms were all pointing to MS but that should not be the case because Mr. K was from the islands, a black man. He was advised to cut all his activities in half. Acquiring the disability had a significant impact on his lifestyle and career.

“I have not been drumming as much as I should be. I actually went right off in 1998. I stopped doing all my work. I used to go into the schools and take the drums and have a workshop with the children where they would participate in the rhythms. We would do certain chants from the islands of Africa. They were very happy with that. I know it has nothing to do with my diagnoses, it’s just depression. I just stopped everything that I was doing. Now, I’m trying to get back into my drumming.”

At age fifty, he is a father of six the youngest of whom is three years old. He is relatively satisfied in his role as a father. His wife is the primary caregiver of the toddler. Although he is unemployed at the present, he is a traditional man of the house. He occasionally goes out on his scooter to buy groceries. His contribution to the household routine involves playing with his daughter at home. He does not take her out alone because she is at an age where she is quite active and thus he is concerned about managing her in public places. He feels that a fixed income limits his social/recreational activities with his family. However, he is not very concerned.

Ms. F.

Ms. F. is a single mother of ten children, four of whom are between seven and thirteen. She acquired her disability during her seventh pregnancy as a result of violence. Her disability is invisible. It creates chronic pain and limits her mobility and thus her capacity to be employed.

As a single parent with a disability, and a large family, she experiences many barriers. These barriers are even greater for her because she is deemed ineligible for many services since her disability is not visible. The barriers she experiences include lack of transportation and lack of financial independence. Social housing does not appropriately meet the housing needs of large families and therefore housing is a barrier for her. Ms. F.'s family is divided between two homes. She also has children with special needs. She requires many supports given her unique situation. Although she possesses the capacity to advocate for herself and her family, she finds that supports and services are not responsive or flexible toward her family's circumstances.

Ms. F. requires support in doing daily living tasks and she has to depend on her children for support in completing chores around the house. This creates tension between the mother and her children. Disciplining her kids by grounding them or sending them to their room is not an option when she requires them to be there for her and support her in the daily household routine.

“My role in the household is a parent role... my children are co-parents because I'm a single parent and there are things that I can't do. I just rely on the kids to do them for me.”

Transportation is one of her biggest barriers in many ways. Living off a fixed income, she often finds herself being forced to get food from the local food bank. However, the food bank hours conflict with her children's school schedule and she has no one to help her carry the food home.

“I go to a food bank. There aren't enough resources to get me where I want to go, just as it is for a lot of people with disabilities. It just seems that if you're not in the majority, have a minority disability, they can't justify the funding to get you what you need so therefore, you have to fend for yourself. A lot of times, that's the situation I'm left in. It makes it very difficult and frustrating. When you ask for help, if your disability is not obvious, people don't want to help you. You have to go in and explain and hope somebody is in a pleasant mood. On a daily bases it's begging. I've been doing that for many years now. I'm tired of it. Somedays I just wake up and say, I can't do this today, and I don't. Then things start to pile up and once again I have to some how find the motivation to get out there again and do what I have to do. Get into a grocery store, get here or there and have that support to carry the packages home because I can't do the bending and lifting and I can't always beg for the help. I can't take my kids out of school to help me with these things every time; it's not practical. The little ones are not able to help me enough and the big ones are in high-school with demanding schedules so it makes things very difficult.”

Again as a result of the barrier of transportation, Ms. F feels isolated from her cultural and faith communities. She is unable to access transportation to attend activities with her family. Public transit is a challenge. She cannot afford a vehicle and cannot access volunteers to drive her large family.

Mr. S.

Mr. S. became almost totally blind at about the age of seven and has been living in Canada for twelve years. His wife is a person without a disability and they have a four year-old son and a new born son. Both are working full-time and have no other family support. Mr. S. has a master's degree and lots of voluntary and religious involvements.

Although Mr. S. helps out with the cooking sometimes, his wife is the main care giver and takes care of everything. She arranges everything before leaving for work and he gets his son ready in the morning and gives him his breakfast.

“She’s the main caregiver and homemaker plus she basically does everything else that I can’t do. When the kids are sick, she may be giving medicine and things like that. Plus reading for me sometimes. It’s a lot of work for her.”

As a result of his capacity to advocate and access information, he receives transportation through an accessible transit service. He takes his son on the accessible bus to work and drops him off at the onsite daycare. Through accessible transit, he is able to take his son to religious services and other social activities independently.

As a family, they go shopping together on the weekends and enjoy leisure walks. They regularly read together to their son. His wife is learning to ride a bicycle in order to teach their son how. He used to take his son to swimming classes before his wife started to work evenings. He would like to take his son to more activities like gym, but his wife does not drive and accessible transit “isn’t as simple as getting into your own car”. He would also like to read more to his son and teach him how to write. Teaching his son how to write and teaching him computer games are very visual activities and thus difficult to guide. He would like to do more activities with his son but he stated that, “accessible games and books in alternate format are too expensive.”

Transportation also poses a barrier in accessing immediate health care. He often finds himself having to pay for a taxi in order to access healthcare for his son regardless of the cost involved. Mr. S. feels that accessible transit has too many constraints around who else can travel with him and when, unlike mainstream transit services, again limiting his activities with his children.

“Having no vehicle means you cannot change plans instantly or be spontaneous. You are vulnerable when there are last minute changes.”

Mr. A.

Mr. A. and his wife are both deaf and have two hearing children. They came to Canada as refugees in the mid-1980s. As a deaf person he had difficulty finding employment in his country of origin. He is successfully employed full-time here. His wife stays at home and plays the traditional role of taking care of the family and household. Mr. A.'s role in the household involves reading and teaching his daughter, taking his kids and wife to appointments and taking his wife shopping.

His daughter was born in Canada. He spends lots of quality time with her teaching her his mother-tongue, sign language and English. He helps her with her homework. He lip reads and goes to the mosque regularly. He started to learn about religion after coming to Canada. Since English is his third language, he finds it difficult to learn by lip reading. However, he reads a lot and spends time teaching his daughter about religion. When helping his daughter with homework, he struggles sometimes again because of the language and his daughter has to be patient.

“I know she has to be patient with me and I don't understand a lot, I realize that she has to be very patient with me because of the English barrier that I face and she needs the teachers to know, let the teachers know that I'm deaf and that she might need a little more encouragement from them because of my disability.”

The teachers are aware of the parents' communication barriers and conversations with teachers are brief. Sometimes, he takes his daughter to the pool to interact with other kids. As ASL interpretation is not always available, his son often accompanies them to teacher interviews and medical appointments to interpret.

Ms. T.

Ms. T. is a single mother of two children. She was diagnosed with Retinitis Pigmentosa (RP) in her mid-twenties. The vision loss was mild. It did not impact on her much initially because she was a housewife and her husband was with her all the time when she and the children went out anywhere. Her husband drove them everywhere. It was only noticeable to her when she could not read the buttons on the VCR. Her family moved to India after the children were born. She was abused and finally decided to leave and come back to Canada. She had no family or friends here. When she arrived with her two young kids, they went to a shelter. She received social assistance through Ontario Works with a rental portion of \$520 and found a basement apartment for \$700. She spent most of the food money on rent as well as other urgent necessities.

“I remember the first year was so terrible because there was snow out there. I couldn’t walk. My kids were little; my son was two and half years and my daughter was four. I had to walk with the groceries. The kids didn’t have proper clothing and I didn’t have proper clothing. Sometimes I would have to go without food because I have to pay the rent and get some over the counter medications which were not covered under ODSP...”

She has received occasional volunteer help through a disability service provider. However, it is very difficult to find a dedicated volunteer who can be there consistently. If she could sponsor her mother to come and live with her, she would be able to accommodate herself. Unfortunately, her financial circumstances are a barrier regardless of the support this would create for her. She attempted every avenue for advocacy assistance.

“Everybody said we can’t get involved and you have to have your income up to \$38000 to sponsor her. I said to them ‘I can make that much one day but I have to start some where. Right now this is the time I really need the help and I can assure you I will not be on assistance. I will start working and my mom will never be a burden on the system if only she can come here.’ It would be a big help. Financially I wouldn’t have to pay for babysitters, and physically as well and emotionally as well. But nobody cared, I tried and nobody listen.”

Mrs. O.

Mrs. O. is a successful career woman and mother of two girls ages nine and seven as well as a toddler. She is a paraplegic and her disability is progressive. She began using a wheelchair when she was pregnant with her youngest girl about three years ago. Her husband has a hidden disability. He experiences moments of clinical depression frequently.

Mrs. O. always depended on her husband for support in her daily living routine in the household as well as in the nurturing of her children. She began recognizing that this dependency strained her relationship with her husband. She purchased some in-home childcare which helped her get by and at least ensure a limited structure for her children and maintain her job. She purchased services from a parent in the community to drive her kids to school. However, this was not enough to create a healthy and nurturing lifestyle for her young children.

Mrs. O. began accessing home care services after she finally admitted that personal care was a challenge for her after she became pregnant, and she also realized that her financial resources could not buy the amount of time she required for supporting her. Mrs. O.'s cultural and faith background contributed to her need to protect her privacy and her resistance to receiving personal care from outsiders. However, she found that given her dynamic lifestyle she required supports that were more flexible to her requirements. The constant orienting of new personal care workers could not fit in to her hectic schedule. Although she worked from home, her IT career had a very demanding daily schedule. She found herself at the brink of a disaster when she finally admitted that she needed greater and flexible supports. Her job was in jeopardy. Her family was in crisis. She began advocating for herself to receive direct funding to manage her own care and was ultimately successful in having her plea heard.

“O’ my God. I can’t believe the difference in my life. Why didn’t I access this program sooner! I finally am in control and not at the mercy of others. I have time to nurture my kids appropriately. I am independent. I am living.”

As a result of the services she directs from individuals whom she employs, she has increased her community and faith-based involvements for herself and her family.

“I stayed away from the community and the mosque because I felt vulnerable with my kids. Too many people watching my every move and passing judgment about my disability if any incident of frustration took place between me and my kids.”

She feels more secure in her community involvements because she has someone to assist her. There is greater structure in her household as well. She is not dependent on family members to assist her in her role as the mother.

Analysis

The ethnocultural and faith backgrounds of parents with disabilities impact on the types of supports they require because their cultural and faith beliefs shape their lifestyles and daily living routines. Sometimes they are concerned about the support providers' lack of cultural familiarity and this becomes a barrier for individuals from ethno-cultural backgrounds accepting services for fear of compromising their privacy, dignity, hygiene, cleanliness or gender specific care requirements.

Attitude about disability creates barriers for parents with disabilities, particularly where both parents have visible disabilities. The educational system and the child welfare sector lack awareness about persons with disabilities and take unwarranted and discriminatory actions assuming that parents with disabilities are likely to be negligent in their parental responsibilities.

Transportation is a barrier for parents regardless of the type of disability if they do not have access to a vehicle within the household. Individuals, whose disability does not prevent them from driving, often are unable to financially afford a vehicle because of their low income status. Alternative transportation like a taxi is costly regardless of the individual's financial status, but in urgent situations is the only available option. Special transportation has eligibility criteria which create barriers for access in terms of the individual's physical capacity. It also has too many restrictions that limit family and children from accompanying individuals on the accessible bus. Special transportation considers the individual's needs regardless of the individual's family responsibilities. Therefore, activities that a family would regularly travel to as a family become very limited if one of the family members is dependent on special transportation.

Housing is a barrier for large families. The social housing system in Ontario does not accommodate large families appropriately and therefore is a barrier for many immigrant families. Accessible housing similarly accommodates the individual's needs, not their family responsibilities. For many immigrant families, the extended family lives together as one household. A person with a disability requiring accessible housing is often forced to live apart from the family if the family cannot afford to make the familial home accessible.

Nurturing supports like homemaking and assistance in the community are required by parents with mobility disabilities and vision loss in the early child rearing years. Parents with disabilities are not receiving the same services. The fact that a parent who is blind receives homemaking services is an exception to the standard of eligibility. A parent with a physical disability managing her own care is able to better nurture her children and is less vulnerable. The feeling of vulnerability during the nurturing years for a parent with a disability is present regardless of the type of disability. Services required to assist with nurturing are time sensitive interventions and are certainly not an indefinite demand on social services.

Immigration is also a barrier for immigrant families. Parents with disabilities would have traditional extended family supports to assist them in their daily living routine and with the nurturing of their children in their countries of origin. However, the extended family supports are not available as a result of immigration sponsorship requirements.

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Financial status impacts on lifestyles. Low income status increases the barriers parents with disabilities face. Transportation requirements in important, urgent or unpredictable situations often have to be resolved and are costly. However, in emergency medical circumstances, parents with disabilities have to use their limited financial resources to take taxis. Parents with disabilities who have the financial capacity to purchase some homecare, attendant care or childcare can accommodate some of their nurturing and daily routine requirements. Thus, the standard of living for parents with disabilities and their families is incomparable to that of parents without disabilities and their families because they do not have to use personal financial resources to purchase basic supports.

Parents with disabilities who depend on their children to accommodate their daily routine strain the parent-child relationship. However, as the children do get older, parents with disabilities agree that their accommodation requirements for nurturing, home making and transportation will change and or lessen.

Recommendations

The following recommendations are intended to improve the lives of parents with disabilities and their child rearing experiences. Legislative policy makers, social policy researchers and disability rights organizations are asked to support these recommendations and take initiative to promote their implementation.

Resources should be allocated through provincial and federal programs to implement a public awareness campaign in order to address general misperceptions about persons with disabilities from diverse backgrounds who are parents.

The education system and child welfare services should be required to undergo training to address attitudinal barriers that parents with disabilities encounter.

Special transportation for persons with disabilities must revise eligibility criteria and escort policies in order to give greater consideration to individuals with disabilities who have families and young children.

Social housing and accessible housing programs must give consideration to large families and make available accessible and affordable housing to accommodate the needs of these families.

Immigration policies must give consideration to persons with disabilities sponsoring a family member to assist with nurturing and homemaking given the fact that this would be a social welfare cost trade-off.

Tax regulations giving consideration to credits for purchasing nurturing supports should be implemented. This would ease the pressure on parents with disabilities who have some capacity to purchase services to assist them with child rearing.

Nurturing assistance is essential in the early years for parents with disabilities, particularly mothers with disabilities. Provisions must be made to take a holistic approach to assessing eligibility for such a program and not limit such a program to only persons with disabilities who require personal care. The direct funding model of attendant care and nurturing offered to an exclusive group of individuals with disabilities requiring personal care should be reviewed and expanded as a model for parents with disabilities regardless of their personal care requirements and recognized as an essential intervention for the early years in raising and rearing children.

Conclusion

Parents with disabilities from diverse backgrounds face different and greater barriers given their ethno-racial/ethno-cultural backgrounds, faith, gender, financial status, family composition and type of disability. The supports and services they receive as a result of the type of disability vary. As parents, persons with disabilities have some similar requirements. Therefore, all parents with disabilities, particularly mothers with disabilities, require some assistance in the early years of their parenting responsibilities.

Appendix A: Contact Information of Partners

For additional information and resources about parenting or to connect with parents with disabilities, please contact the following organizations.

Parenting with a Disability Network (PDN)
The Centre for Independent Living in Toronto (CILT)
Tel: 416-599-2458
TDD: 416-599-5077
Web: www.cilt.ca

Ethno-Racial People with Disabilities Coalition of Ontario (ERDCO)
Tel: 416-657-2211
Toll-free: 1-888-988-3999
Web: www.ryerson.ca/erdco

Appendix B: Consent Form

Project Title: Parenting With a Disability: Diversity, Barriers and Requirements

Description:

If we are to ensure that parents, regardless of race, culture, class and ability have a positive parenting experience and pursue healthy lifestyles for their children's early years, it is important that we understand their support requirements and ensure that social policies and programs reflect these needs/requirements. This qualitative research study will gather profiles of parents from different backgrounds with different disabilities, to tell their stories describing their barriers and requirements, analyze the gaps in supports and make recommendations for further research. It is hoped the findings from this project will foster innovative policy changes to meet the support requirements of parents with disabilities.

Comparative portraits will be developed to explore barriers and requirements for formal and informal supports parents with disabilities require in accessing supports and services given their disability; their ethno-racial/ethno-cultural background; their family structure; their faith and community links as well as their socio-economic capacity. The research will examine a number of supports and services. These include: health services, education, social recreational activities and employment.

This research initiative is made possible through a grant from the Canadian Centre on Disability Studies, a consumer-based disability organization which focuses on research and education in the area of Disability Studies and is located in Winnipeg, Manitoba.

Rabia S. Khedr of DiversityWorx as the principal investigator is conducting this exploratory research project. She requests your consent to participate in an interview or focus group.

If you are an ethno-racial/ethno-cultural person with a disability parenting a child or children age 13 or under, you are invited to participate in a 1 to 1 ½ hour face-to-face or telephone interview.

If you are a key informant working as a service provider or community advocate, you are invited to participate in a 2 hour focus group meeting.

As a voluntary or independent participant taking part in this research, you will receive a \$50.00 honourarium for your participation in order to compensate you for any disability-related or childcare costs you might incur as a result of participating in an interview or focus group. Please note that you are free to withdraw from the study at any point in time without penalty.

The information you provide in the interview or focus group will be available to the principal investigator for the purpose of this study but it will be kept confidential. Information shared in a focus group is also confidential and participants are asked not to share it outside of the focus group discussion. If you are to be quoted in any form, verbal consent will be obtained from you prior to using the quotes in the study.

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Should you require further information, please contact Rabia Khedr at 905-270-9679 or email her at rkhedr@diversityworx.com.

Please indicate your participation: ____Structured Interview ____Focus Group

I agree to participate in the project entitled “Parenting with a Disability: Diversity, Barriers and Requirements.”

Signature:

Date:

Researcher:

Date:

Appendix C: Interview Questions

1. Could you please tell me a little about yourself?

- a) What is your disability?
- b) Describe your role in the household?
- c) Are you working?
- d) Describe your community involvement?

2. Tell me about your family.

- a) How many children do you have and how old are they?
- b) Describe role of spouse if applicable?
- c) Describe your social/community involvements?

3. Tell me about your daily routine as a parent.

- a) Describe your household work?
- b) Describe your work in terms of the children?

4. Do you currently receive help from family members or anyone else to assist you in your daily/weekly routine as a parent?

5. What do you do in your routine as a parent and what do you want to do?

6. Describe your involvement in:

- a) Accessing health services for your children, going to the doctor with them, etc.
- b) Your children's education, going to the library with them, doing homework, meeting their teachers, etc.
- c) Community fun for your children, social/recreational activities, swimming lessons, leisure walks, cultural/spiritual activities, etc.

7. What supports or services have assisted you in your role as a parent in insuring a healthy relationship with your child/children?

8. Describe your satisfaction in your role as a parent.

- a) as a nurturer
- b) as a discipliner
- c) as a teacher or friend, etc.

9. Are there things you want to do with your children that you are not doing at the present time?

- a) What are those things?
- b) What supports/services would help you do those things?

10. Other comments about your quality of life as a parent with a disability.

Appendix D: Focus Group

July 19, 2005

Ryerson University

Facilitator: Rabia Khedr

Questions:

1. How do you feel about the themes and patterns that have emerged? Do they reflect your experience or knowledge?
2. What other themes or patterns should be included in the report?
3. What recommendations do you feel can address the themes and patterns and to whom should they be directed?
4. What other comments or suggestions do you have?