The Ethno Racial People with Disabilities Coalition of Ontario (ERDCO)

We Are Visible...
Ethno-racial women with disabilities speak out about health care issues

(A needs assessment about health care issues and their impact on ethno-racial women with disabilities)

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Section 1 – Introduction

1.1 The Project Sponsor: ERDCO

ERDCO (Ethno-Racial People with Disabilities Coalition of Ontario) is a consumer controlled, non-profit community organization. ERDCO was founded in 1993 and incorporated in 1994. ERDCO is philosophically committed to working within an anti-racist framework and on the belief that all people with disabilities deserve to be respected, to live with dignity and be full participating members of society. To this end ERDCO is committed to promoting respect for ethno-racial people with disabilities. Today, ERDCO has an active membership of over 200 people, including women, children, youth, seniors, single parents and parents of children with disabilities. ERDCO represents ethno-racial people with disabilities of all ages, racial, cultural, linguistic and religious backgrounds.

1.2 The Women’s Health Project: Goals and Objectives

"I am tired of being treated like I am invisible. I am a woman and I do not want to be treated like a child or an object. I have hopes, desires and ambitions just like anyone else."

~Participant in the Women's Health Project

In 1995, ERDCO received funding from the Ministry of Health, Women's Health Bureau to undertake a project called, Barriers To The Health Care System for Women of Colour, Refugee and Immigrant Women with Disabilities. This project is now known as The Women’s Health Project. The Women's Health Project was implemented with the following goals and objectives:

• To identify the barriers to health services experienced by women of colour, immigrant and refugee women with disabilities who live within the Metro Toronto area.
• To provide community based forums that would allow ethno-racial women with disabilities to speak freely and openly about the problems that they encounter when accessing health services.
• To encourage, through the use of community consultations and focus groups, ethno-racial women with disabilities to break their isolation and allow them to take a proactive stance towards sharing information about health care resources.
• To identify the multiple ways in which racism, sexism and systemic barriers impact upon the lives of ethno-racial women with disabilities.
• To allow ethno-racial women with disabilities an opportunity to hear the voices of other women from their community and allow them to share coping strategies and other essential pieces of information.
• The final objective of the project is to identify areas that require future research and to recommend ways of improving health care services for ethno-racial women with disabilities, in a manner that is respectful, culturally appropriate and dignified.

1.3 The Women’s Health Project: Context and History

Within the context of the Disability Movement, The Women's Health Project is unique. The Women's Health Project represented an opportunity for women who face multiple barriers, both physical and systemic ones, to identify these barriers and discuss the impact that they have on their health and health care. The Canadian Disability movement is recognized by activists to be at the forefront of disability organizing. In Canada, women with disabilities have assumed positions of leadership within the context of the Disability Movement and have organized to educate the public and bring an awareness of women's issues to the center of the Movement.

DAWN

In 1984 the first provincial DisAbled Women's Network (DAWN) was formed. In 1985 the national organization called DisAbled Women's Network (DAWN) Canada was formed. Since that time, DAWN has produced important works on topics such as sexuality, violence, gender equity and unemployment. In various reports and workshops DAWN has examined the impact of these inequities on the lives of women with disabilities. They have brought disabled women's issues to the forefront of public consciousness and produced ground-breaking work in the area of violence against women with disabilities. Thanks to DAWN, topics that had previously been marginalized or ignored by mainstream feminist movements and the Disability Movement have been given a new focus. However, within the context of the Disability Movement the specific issues that ethno-racial women with disabilities experience has often remained unexamined. For ethno-racial women with disabilities their experiences in the world are often defined by double or triple oppression. Thus, The Women's Health Project is an initiative that aims to bridge existing gaps in knowledge and hence build a more complex understanding about the intersections of disability, race, ethnicity, language, culture and religion.

Erosion of the Social Safety Net

In the decade since the formation of DAWN important steps have been taken towards bringing disability issues to public consciousness. Today, however, economic uncertainty is becoming the norm and many communities are facing economic vulnerability and uncertain futures. Within the context of the current social and political climate ethno-racial women with disabilities are particularly vulnerable. Today in Canada we are witnessing a move towards less government intervention into every aspect of our lives. As a result, all levels of government are undergoing radical

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restructuring and downsizing and transfer payments to the social services and health sectors are being cut at a level that has never before been witnessed.

What does this new era of economic uncertainty mean for ethno racial women with disabilities? As we enter into a new era of government cutbacks and elimination of services we must radically rethink old approaches to health care, services and job creation. Old tried and true measures no longer work in this new era of cost effectiveness. New questions are emerging, such as how can communities and agencies such as ERDCO help to deliver cost effective programs and services? Throughout the community consultations, it became apparent that for ethno-racial women with disabilities a woman's health was directly impacted by her access to education, jobs and services. Many women identified gaps in the knowledge base of service providers and noted that attitudinal barriers were frequently a source of unnecessary misunderstanding. Racism, as well as ignorance about disability issues was also identified as a frequent barrier to health. It is often in the intersections of race, disability, culture and language that ethno-racial women with disabilities find their concerns marginalized.

This consultation is an attempt to define the health care needs within the context of a community that thus far has had few opportunities to voice its concerns and needs. As more and more demands are made on the health care system during a period of decreased funding it is apparent that community agencies and existing services must fill in the gaps. Where are these gaps? This consultation attempts to identify the gaps and highlight areas of concern, this will allow us to educate health care providers on the health care needs of women with disabilities in a manner that is efficient and appropriate in this new era.

In 1995, DAWN Toronto was forced to close. During the same time period the Canadian Disability Movement found itself fragmented as service after service lost funding and was forced to shut down. In the same time period cuts to Wheel-Trans, Home-Care, changes to the Canada Pension Plan (C.P.P.), Unemployment Insurance, General Welfare Benefits and Family Benefits have shaken the economic well-being and security of many women. These changes often hit poor women the hardest and of the poor, statistics indicate that ethno-racial women with disabilities are statistically located at the bottom of the economic ladder. Additionally, the public pension system is being massively overhauled by our federal government and the outcome of this may adversely affect women with disabilities. It is in this climate of cutbacks and elimination of services that ERDCO is attempting to re-vision how we educate service providers and what can be done to allow services to be delivered efficiently and effectively.

Why is it important that we hear the voices of ethno-racial women with disabilities?

- Women with disabilities are three times more likely to experience violence than non-disabled women.
- Women with disabilities are more likely than non-disabled women to be unemployed.
• Women with disabilities are more likely to be misdiagnosed in health care services than non-disabled women.²

Many of these facts and statistics are entering into public consciousness and an awareness of the systemic barriers facing disabled women is currently being examined by disability rights groups, the government of Canada and various provincial organizations. The Women's Health Project however, asks questions about the specific impacts that these aforementioned barriers have on the lives of ethno-racial women with disabilities. For example:

• How do women for whom English is not a first language cope with health care services?
• How do ethno-racial women with disabilities manage the complex interactions of racism and sexism in their lives?
• What are the specific barriers to health care that ethno-racial women with disabilities face and how do these barriers impact on their quality of life?

Ethno-racial women with disabilities face ongoing, daily and systemic discrimination in the form of racism. This is itself a daily exposure to violence. Ethno-racial women with disabilities who experience racism in the context of the public transit system or in the health care system face double or triple oppression. Racism is a barrier to health. Racism is a form of violence that curtails, limits and adds stress to the lives of women with disabilities. Within the context of this belief system it appears that racism as a form of violence needs to be re-framed in the public consciousness as an act of violence that will not be tolerated. Many women in the course of this community consultation spoke about their sense of frustration and exhaustion at being forced day after day to deal with racist assumptions and remarks from the very people that they rely upon to provide them with health care services and access to these services. Ethno-racial women with disabilities face daily harassment in the form of physical barriers, attitudinal barriers and systemic barriers.

Women with disabilities and systemic barriers:

• Women with disabilities experience discrimination because they are women and because they are disabled.
• Ethno-racial women with disabilities face discrimination because they are women, because they are disabled and because they are people of colour for whom racism, language barriers and other systemic barriers also interact to limit their full and equal participation in society.
• Ethno-racial women with disabilities face barriers to health care in the day-to-day management of their lives.
• They face systemic barriers that translate into chronic unemployment for them as a group. If they do have meaningful employment many face negative attitudes in

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the workplace and reluctance on the part of their employer to provide accommodation or a culturally sensitive environment.

- Changes to C.P.P. and private insurance plans also mean that many women who are able to work only part-time are disenfranchised because of rigid and outmoded regulations.
- Marital disincentives that are built into long term disability benefits and social assistance for disabled women translates into a barrier.
- Limitations in the Canadian Immigration Act regarding people with disabilities mean that family separation becomes an issue.

Many of the women who participated in this project spoke frankly about the ongoing violence of sexism and racism and how these two forces interact in their lives. Racism is violence and an ongoing barrier to health for ethno-racial women with disabilities.

The Women's Health Project is unique because no other study or community consultations specifically target the barriers to health care experienced by ethno-racial women with disabilities. On the pages to come you will read the words and hear the voices of the women who participated in this project. These are the testimonials of the women who participated in the project and when it comes to each woman's particular disability it is important to remember that she is an expert on her needs and on her disability.

1.4 Statistics

According to the 1986 Census, over 2 million Canadians identified as members of racial minority groups. In the Metro Toronto area alone over 30% of the residents are members of ethno-racial communities. Yet, despite ongoing legislative attempts to enshrine notions of equality and non-discrimination into our legal and human rights codes members of ethno-racial communities continue to face systemic barriers in the institutional systems of our society. In Canada we have the Charter of Rights and Freedoms, the Human Rights Codes and the Multiculturalism Act. Yet, systemic barriers persist and ethno-racial people must continually struggle against misperceptions and prejudices that result in their under-employment in the labour market.

According to the Business & Labour Market Analysis Group, Statistics Canada, 76% of visible minorities are employed as compared to 83.3% of whites. Presently it is difficult to obtain statistical records that indicate the exact number of people with disabilities in Canada, according to a statistics Canada 1985 Health and Activity Limitations survey (HALS) over 16% of the general population identified as having some level of

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disability. It is further estimated in the HAL survey that 14% of the population in Ontario has some form of disability. In addition, the HAL survey reports that one in 15 women in Ontario are disabled, and labour force participation of women with disabilities is at the rate of only 39% compared to 59% for both men and women.

One must be cautioned however from assuming that unemployment or under employment is the result of a woman's inability to work. Often, it is barriers to access in the workplace that prevent a woman with a disability from working to her full potential. Thus, attitudinal barriers determines how society reacts and treats a woman with a disability and a woman with a disability need not be disadvantages, unemployed or under employed.

The HALS is a detailed survey that allows us to link HALS information to the census data to compare disabled and non-disabled populations for categories of information gathered according to the census. According to the 1991 HALS, people with disabilities face multiple systemic barriers in our society. For ethno-racial women with disabilities these barriers are compounded by racism, sexism and linguistic and cultural barriers. In Metro Toronto there are over 300,000 women with disabilities.

- 52% of people with disabilities are unemployed or not in the labour force.
- 56% of people with disabilities reported being limited in the workplace or completely prevented from working.
- 63% of people with a moderate disability and 80% of people with a severe disability have never had a job.
- 60% of people with disabilities earn less than $10,000 per year.
- About half of women with disabilities earn $5,000 a year or less.
- 63% of people with disabilities have a level of schooling of secondary or less, while 36% have some post-secondary schooling or more.
- Comparable figures among the population without disabilities are 51% and 49% respectively.
- Canadians with disabilities who receive social assistance live below the poverty line in every province and territory.

**Barriers to Employment**

Statistics indicate that women with disabilities, as a group, experience systemic barriers to education and the labour market. This translates directly into a health care liability. Income and education level often determine the level of access we have to medical care, mobility services and can also represent barriers to participation in recreational and leisure activities. All of this impacts upon health and well being. Disability, gender and race are all factors that contribute to lower socio-economic levels for women with disabilities.

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Barriers to employment can include attitudional barriers, inaccessible building locations, obstructed washrooms or the lack of public transportation for women with disabilities. For ethno-racial women with disabilities existing barriers to employment may be compounded by attitudinal barriers informed by racist or cultural stereotypes. For example, an ethno-racial woman with a disability who also wears the hejab may find herself facing physical barriers to the workplace, attitudinal barriers about her disability as well as cultural and racial stereotypes about her culture and religion. All of these impact directly on a woman's health, by limiting her access to services, jobs, education and limiting her access to adequate health care.

Canada's Changing Demographics

Canada's demographic base is rapidly changing. 9.4 million people, representing 39% of the Canadian population reported in the 1990 census as having ‘some non-British or non-French’ ethnic origins. Additionally 3.5 million Canadians reported languages other than English or French as their mother tongue. If present trends continue, Statistics Canada estimates that 10% of the Canadian population will be from racial minority groups by the year 2000. Ethno-racial women with disabilities are not an invisible or silent minority in the social life of Toronto.

Ethno-racial women with disabilities are our co-workers, neighbours and are represented amongst some of the most distinguished community leaders. Yet, women of colour, refugee, immigrant women and women with disabilities continue to experience ongoing discrimination on the basis of age, gander, ethnicity, colour, language and level of ability.

Ethno-racial women with disabilities rarely see positive representations of themselves in the media, in the health care services that they access regularly or in any area of public life. Within the context of the health care system and in the myriad of publicly and privately funded services that ethno-racial women with disabilities access daily and support through their continued usage, they routinely encounter racist, classist and sexist assumptions about their bodies, culture and ability.

It is ERDCO's belief that health care must be accessible to all women. It must be accessible in a manner that is safe, healthy and respectful. Health services must be accessible to women of all types of disabilities, including physical, deaf, blind, learning, emotional, and psychiatric survivors. Women should not feel guilty or ashamed of their disability when they are accessing health care services, especially when asking for accessible service delivery. Often women face attitudinal barriers from service providers that make them feel as if they are imposing when they request accommodation due to their disability such as an accessible examination table or attendant services. In addition, an ethno-racial woman with a disability who requests accessible services might be reluctant to request a language interpreter or a culturally appropriate setting.
A woman’s location in terms of ability, race, culture, sexuality and class all determine ability to access services, jobs and education. It is through highlighting an awareness of these differences and by speaking out about our needs that we can further improve and educate services, providers and community organizations about providing better, more efficient, safer and culturally appropriate services.

Section 2 – Definition of Terms

ACCESS means that members of an ethno-racial group have opportunities and means to participate actively in the organizations established for their benefit as clients or consumers, staff members, volunteers, and board members. (Action, Access Diversity!)

ANTI-RACISM is an approach that confronts racism in all its forms, based on the assumption that racism has to do with power structures and is caused by historical, social, cultural, political, ideological and economic factors. To combat racism we need to identify and change systems which maintain racism. (Hear What We're Saying, Shaheen Ali)

BARRIERS refers to limitations on people having access to services, including inadequate staff resources and insufficient service provision, lack of language skills and interpreter services, lack of awareness of services available, physical location of services, administrative practices, inappropriate and/or culturally insensitive attitudes of service providers, etc. (Action, Access, Diversity!)

CULTURE is the ideas, beliefs, values, activities, knowledge and traditions of a group of individuals who share a historical, geographical, religious, racial, linguistic, ethnic or social context, etc. A culture is the total of everything an individual learns by being immersed in a particular context. It results in a set of expectations for appropriate behavior in seeming similar contexts. (Culture & Disability, Rafia Haniff)

ETHNICITY refers to a shared culture or to a people who identify themselves and/or are identified by others as belonging to the same group. (Action, Access, Diversity!)

ETHNO-RACIAL GROUP refers to all individuals having an ethno-racial heritage. This term is used to refer to groups of people with shared ethnicity or race. The term "racial" is stated to reflect the reality that, for some groups, race may the dominant factor in their identity. (Action, Access, Diversity!)

ETHNO-SPECIFIC AGENCIES are organizations which are mandated to serve one or more specific linguistic, racial, cultural, national and/or ethnic groups. (Action, Access, Diversity!)
**MAINSTREAM AGENCIES** are broad based organizations which are mandated to serve the community-at-large. While they may serve significant numbers of clients of diverse ethno-racial backgrounds, they function within the organizational and cultural framework of the dominant society. (Action, Access, Diversity!)

**RACISM** is not an outcome of cultural misunderstanding, it results from unequal power relationships. People who have power do not wish to give it up. Underlying these power relationships is the belief that some groups are inferior because of skin colour and are therefore not entitled to exercise power. Racism includes attitudes, actions, social structures and policies which exclude people of colour and First Nations people from equal participation in society. (Hear What We Are Saying, Shaheen Ali)

**SYSTEMIC DISCRIMINATION** “describes the fact that many employment (and other) barriers are hidden, usually unintentionally, in the rules, procedures, and sometimes even the facilities that employers (and organizations) provide to manage their human resources (and operations). Discrimination can result if these ‘systems’ encourage or discourage individuals because they are members of certain groups, rather than because of their ability to do a job that the employer needs done” (Employment Equity: A Guide for Employers).
Section 3 – Methodology

3.1 Project Structure

Participatory Research:

The Women's Health Project was a grassroots participatory research study. The findings are compiled based on a qualitative research style. This allows the reader to hear the actual stories of the women who participated. There were two sample groups in the study: (a) ethno-racial women with disabilities; (b) health service providers. Two separate questionnaires were developed and distributed to both groups. The questions were developed by Mala Naraine, co-ordinator of The Women's Health Project. Focus groups were conducted with both members and service providers. The questionnaires were also distributed to the general female membership of ERDCO thus allowing women who were unable to attend the focus groups an opportunity to participate. Telephone consultations were also conducted.

Community Outreach:

Rafia Haniff and Nora Shankar both did extensive community outreach. Linda Cornwell, the Community Health Care Worker at Women's Health in Women's Hands, provided invaluable assistance and advice as a member of the Advisory Committee. In addition, she allowed us ongoing access to her agency's resource center. Gloria Blair, an ERDCO member assisted in recruiting women to participate in a focus group at Variety Village, in Scarborough. This was to be a very informative afternoon of information sharing, personal narratives and laughter.

Providing a Safe and Comfortable Environment:

The use of focus groups allowed women who felt comfortable in a semi-public setting to share their experiences. Focus groups aimed to provide a warm, supportive and comfortable environment, in which the safety of the women was primary. Women's Health in Women's Hands, generously provided a centralized, accessible location for these sessions. Women's Health in Women's Hands is an accessible downtown health care centre that is woman friendly and an excellent location for women to come together to share information.

Additionally, Women's Health in Women's Hands generously allowed the use of their resource centre to aid in the writing of this report. The women who participated in The Women's Health Project were encouraged to use the services to obtain any further information they might need.
Questionnaires and confidential telephone consultations were also used in this study. This allowed women who wished to maintain privacy and confidentiality to narrate their experiences anonymously and in the comfort of their own homes. Although the project provided attendant care and transportation for the participants of the project many women were unable to attend focus groups. For some, the winter weather rendered this a difficult task, for others who had small children, the task was too difficult, consequently telephone consultations set at a pre-appointed time were the answer.

**Cultural Sensitivity and Accommodation:**

The focus groups were conducted in culturally and linguistically accessible ways and accommodations were provided. This includes the availability of alternative formats such as Braille, large print, and sign language interpretation. Attendant services and transportation were also available. Culturally appropriate dietary accommodations were made. In addition, the women that participated in the focus groups and the consultations were compensated with an honorarium, thus signifying the value of the contribution of their personal stories and narratives.

The focus groups for service providers were held at Women’s Health in Women’s Hands. Service Providers that were unable to attend a focus group were supplied with questionnaires and an opportunity for telephone consultations. Questionnaires can be found in Appendix A.
Section 4 - Qualitative Findings and Analysis

Part I of the Findings

“I used to feel that no matter what happened to me ... no matter how my disability progressed, that I would always be able to access services and that those services would be available to me. I always felt like I would be able to look after myself. Today, I no longer feel like that, the health care system is eroding to the point that sometimes I feel like agencies and services would just like me to ... go away ... to disappear...”

~Participant in The Women's Health Project

These words indicate clearly the anxiety that ethno-racial women with disabilities are feeling today. The Ontario that we live in today is drastically changed from Ontario of even one year ago. At almost every level of government and health care services are being cut or streamlined. The question “What will happen to me?” is one that resounds throughout this report as women witness the dismantling of the social safety net. In addition to the loss of social services, the end of rent controls and the possible elimination of federal co-ops, we in Ontario have experienced the elimination of employment equity and training programs.

4.1 Discussion Guidelines and Questions

The following questions were used to guide the discussions and consultations to the women who participated in the project:

• How do you ensure that your health needs are met on a day-to-day basis?
• What strategies have you developed to deal with stress?
• Do you use alternative health services?
• Can you name some of the barriers that you have experienced when accessing health services?
• Have you experienced racism when accessing health services?
• Can you name any services that would help to accommodate your health needs?
• Do you feel that you have adequate access to information of health services?
• What could be done to help you access information more efficiently?
• Do you feel that you were given appropriate information on contraception and reproductive services to make an informed choice?
• Have you experienced any form of harassment when accessing health services?

The questions were used as a guide to focus the discussions and allow women to share their experiences of health care.
4.2 Summary of Findings

The major findings of The Women's Health Project revealed that health care is not an isolated aspect of a woman's life. A woman's health and well-being are impacted from many areas of public and private life. A woman's access to jobs, training and education are as equally important as her ability to access equitable health services. The following categories highlight the major categories that women identified as barriers to health care:

- Physical barriers such as architectural barriers and limited access to transportation.
- Ableism in everyday transactions, such as handling money.
- Vulnerability to harassment and abuse.
- Inappropriate expectations from medical personnel and health service professionals and lack of knowledge about disability needs.
- Inadequate health care equipment.
- Inappropriate service delivery.
- Privacy and lack of respect for ethno-racial women with disabilities.
- Lack of awareness about sexuality and the impact of culture on disability.
- Negative portrayal of ethno-racial women with disabilities.
- Failure to recognize the right of ethno-racial women with disabilities to bear children and make informed choices.
- Racialization and sexualization of ethno-racial women.
- Sexual harassment.
- A failure to train health service providers on issues of race and culture.
- Discrimination based upon class and socio-economic status.
- Barriers to education and employment.
- Lack of representation in health services and public institutions of ethno-racial women.
- Lack of recognition and failure to address language needs, especially in institutional settings.
- The increasing use of user fees.
- The exorbitant cost of mobility devices.
- Lack of recognition for traditional medicines and alternative health cares.
- Lack of information and community based groups that can provide education, training and information.
- The inability to find centralized information about changes to health care and insurance.
4.3 The Women's Health Project - Findings

4.3.1 Physical Barriers to Health Care

In recent years, building architecture has been adapted to allow people with disabilities better access and accommodation. The first building code requirement in Canada was enacted in 1975. Since then public awareness about the right of disabled people to use public spaces has increased dramatically. However, despite building code regulations that specify the size of doorways, length of ramps and washroom accessibility, women with disabilities frequently face unnecessary architectural barriers. Often these barriers are the result of broken or poorly maintained equipment. Sometimes the barrier is the result of poorly designed architecture and sometimes it is an issue of safety, such as accessible entrances being hidden in unsafe locations such as the back of poorly lit buildings.

Building code regulations require that doorways, aisles and ramps be built to certain specifications. However, in older buildings access is often difficult and accessible entranceways, elevators and other architectural barriers were frequently mentioned by women as daily barriers to their enjoyment of life. Many times women noted, that even if a building is fully accessible, the equipment is poorly maintained:

“... I can't tell you the number of times I have gone to an accessible building and the automatic door is not working…”

“Sometimes in accessible buildings I can get my chair inside the doors, but once in the doctor's office the aisles are so narrow I can't get in.”

“It is clear to me that on the planning committees for accessible buildings and washrooms and doors and all that, that not one single disabled person was consulted. If we were our chairs would fit properly into the washrooms, and doors wouldn’t open outwards slamming into our faces!”

“It is very frustrating to book Wheel-Trans for a doctor's appointment and when you get there the building entrance isn't accessible, this happened to me. It was frustrating because the receptionist knew when she booked my appointment that I was in a chair. It just proves that my needs are not considered by able-bodied people.”

“I am tired of going into restaurants and services through the back door.”

One woman spoke of her ongoing frustration with the accessibility guide book that lists restaurants and public facilities are accessible:
“I am really sick and tired of that book that is supposed to list accessible places. I have been to so many restaurants where I can get in the door, but the washroom is down some stairs.”
“…I wonder if restaurants lie to get into that book, doesn’t anyone check out these things?”

“I went to one restaurant that was listed as accessible in that restaurant guide, I even called to double-check that it was accessible because I had arranged to meet several people there and when I got there... Stairs!”

Automatic doors were a frequent source of irritation for women in wheelchairs:

“At Doctors’ Hospital, the doors don’t stay open long enough for you to enter. . . because of my disability, let’s just say I don’t move very fast, and once those doors almost hit me, knocking me over. The worst part about this however was the group of people, including medical personnel that witnessed this and just watched.”

“I can’t believe that sometimes the doors open towards you, almost hitting you.”

“Very often the automatic doors just don’t work, It seems like the accessible doors, washrooms and rails are so low on their priority that no one does anything when they are broken or in need of repair!”

The automatic doors and other doors have also been cited by women as too heavy. Women have difficulty opening the doors:

“I find that the doors in many hospitals and doctors are so heavy that I cannot open them.”

The following situation indicates that many institutions consider providing accessible services for disabled women and add on and not central to their core funding:

“I went to a conference recently that was held in a building that is well known its support of disabled people and women of colour, and for the entire duration of the conference the accessible elevator was out of service. I actually had to use the service elevator each time I entered and exited and had to get an employee of the building to accompany me. It was just ... frustrating. I thought, I paid money to be here too, I deserve to be treated... better.”

It is frustrating to be forced to change health services simply because the building is not accessible:

“I had a family doctor for many years before I became disabled. But when I got M.S. I had to change my doctor because the building was not accessible. I had to find a new doctor, that I didn’t know, in a building that was accessible.”
Handling money is an everyday task for most of us. Yet, this simple activity is based upon the visual cues provided by currency. For women who are visually impaired women it is a constant irritation:

“Paper money is really difficult to distinguish. It’s my fantasy that one day paper money will have Braille.”

“I would like to have Braille pricing in stores, like just on the shelves would be really terrific. Did you know that in Toronto there is only one store, a Shoppers Drug Mart at Bayview and Eglinton, that has Braille pricing on its shelves.”

Imagine the convenience for a visually impaired woman if she had Braille pricing available to her on store shelves. In addition she would not need to be dependent upon asking others to tell her the price.

Bank machines are becoming a way of life for most of us, however for women in wheelchairs, bank machines are often inaccessible:

“I cannot manage to get my chair to the machines most of the time...I find most bank machines inaccessible. The buttons are out of reach and the strength required to pull out the card is something I cannot manage.”

“Quite often, if I have to use a bank machine, I have to ask someone to help me get my money out and this becomes a safety issue...”

“There is one bank machine at Yonge and Bloor, it is a Royal Bank, that is wheelchair accessible, its keys are low and it has a groove that my chair can fit into...I wish more were built in this manner.”

Transportation was also identified as a barrier, especially for women who use wheelchairs.

“...sometimes I feel like getting Wheel-Trans is arbitrary. I recently got turned down, but I had difficulty finding out why.”

This failure to provide adequate information on the part of service organizations is related to poorly delivered information about services arid de-centralization of many of these services.

Some women are still ambulatory, yet because of their disability they cannot walk for long distances or perhaps not maneuver stairs. Consequently, using public transit is not an option. Yet, many ambulatory women with disabilities are not considered disabled ‘enough’ to use Wheel-Trans:
“It is very frustrating for me because some days it is true, I can walk, but other days I am very weak. I don’t abuse the system but I think there is this perception out there that all black women are abusing it. I feel like people think I’m faking it on those days when I can walk…”

The same woman spoke at length about harassment by a Wheel-Trans driver, who saw her walking one day and accused her of fraud...

“At the time I thought, just go ahead, I know I am not faking and I have doctors to back me up. But, later I became very frightened and was afraid I might be denied services.”

This incident highlights the vulnerability that many ethno-racial women with disabilities feel in day to day negotiations with drivers, workers and providers. This situation highlights the interaction of racism, sexism and ableism that ethno-racial women with disabilities encounter on a daily basis.

Racism from Wheel-Trans drivers was a frequently cited complaint from women. Women with disabilities interact with drivers regularly and frequently encounter racism in these interactions:

“Once I requested a particular location from a Wheel-Trans taxi driver, and he said, ‘Oh, there’s lots of paki’s and immigrants over there.’ This has also happened when I have requested drop-offs at Gerrard Street, or ‘little India’; and drivers have made racist comments about the smell.”

What happens when a woman does complain about harassment:

“I was racially harassed by a Wheel-Trans taxi driver and when I called the office to complain they promised me confidentiality. I am a woman in a wheelchair and I also use Wheel-Trans regularly, so I was concerned about future harassment. Well, confidentiality was not observed and the next time I used the service the driver said, ‘so, I heard you opened your big mouth!’ I was very frightened for my personal safety.”

Women also noted that many drivers did not handle their equipment in an appropriate and professional manner:

“My wheelchair is an expensive piece of equipment and sometimes the way drivers handle it I think they don’t realize that…I think they should receive some training on how to handle our chairs and also on how to put seat belts on disabled women…”

Drivers who regularly provide services to ethno-racial women with disabilities need to be provided with anti-racism training. Additionally they should be removed/and or reprimanded for harassment and racism. If we as a society understand racism as a form
of violence then we will be forced to take stronger actions against people who commit racist act!
Women also noted that health service personnel seemed unaware of the time constraints that a woman who uses Wheel-Trans has on her:

“If I miss my ride because an appointment runs too long then I may be stranded for hours, until one can come. In addition, if there is no accessible washroom available I might be in big trouble. Sometimes the staff seem completely unaware of these issues…”

• Barriers to accessibility means that ethno-racial women with disabilities are barred from fair and equitable health care.
• Barriers to accessibility increases the vulnerability and dependence of ethno-racial women with disabilities on service providers,
• Barriers to accessibility are a barrier to employment, education and recreation.
• Barriers to accessibility are a barrier to the health and well-being of ethno-racial women with disabilities.

4.3.2 Lack of Quality in the Provision of Health Services

It is important to note that the lack of physical access to health care and a lack of quality in the provision of health services are closely connected. The physical barriers that women face when accessing health care translates into a lack of quality in the provision of health services. This point cannot be made more strongly in the case of a woman who described her last physical examination:

“When I got to the doctor’s office for a routine examination it turned out that the examination table was not accessible. My doctor had to put me on the floor to examine me. Can you imagine how long that doctor would stay in business if an able bodied woman had been asked to lie on the floor for her examination?”

In discussions about the architectural barriers that women with disabilities face it became apparent that often the worst offenders are doctor’s offices and hospitals. It is ironic, because it is in these locations that we imagine accessibility would be paramount. Yet, women stated over and over again that doctor’s offices, hospitals and labs are often the most in-accessible locations and the personnel in these facilities are often unaware of the special needs that a disabled woman has:

“Many hospitals don’t even have adjustable beds especially in the specialty labs, such as ultra-sounds ... the last time I went for an ultra-sound the staff just stood there expecting me to leap out of my chair on to their bed!”

Inappropriate expectations from health service personnel and inadequate equipment were also cited as ongoing barriers for many women.

Poorly trained staff in labs can pose a threat to the physical safety of a disabled woman:
“The last time I went for an ultra-sound the technician left the room and my arm fell of the bed ... if my leg had fallen I might have rolled of the bed and seriously injured myself.”

“When I went to Wellesley Hospital recently for an ultra-sound it was an exercise in frustration. First the waiting room was not accessible and they made me wait outside, and then after I had my ultra-sound I had to relieve myself so badly, I was in agony, and guess what? They did not have an accessible bathroom!”

This last incident resulted in the woman being forced to travel by herself around the hospital looking for an accessible bathroom. The laboratory staff was unable to tell her the location of an accessible bathroom. Finally when she complained the attending nurse said, “don’t people in your culture bring family to help them?” What began as an issue of accessibility and accommodation grew into a racialized encounter that illustrates how race impacts on every level for an ethno-racial woman with a disability.

“It’s probably surprising for people to hear this, but hospitals are very behind when it comes to being accessible.”

“For all the wheelchairs, sick and disabled people that you find in a hospital ... it is very shocking to know that often there are no conveniently located accessible bathrooms, that examining beds are too high and not accessible and that attendant care is almost unheard off - despite the fact that women are constantly getting dressed and undressed for the purposes of examinations.”

Many of these situations could be avoided if health care workers and service providers were educated about disability issues. Health care services not only need to ensure accessibility in their architecture but they need to provide trained and knowledgeable staff.

Many of the women who participated in the project stated that they were not satisfied with the health care services the presently receive. Often this was the result of several factors. For example, although women liked their present doctor or doctors, the failure of health care personnel to provide adequate equipment for a routine gynecological examination results in a lack of quality health care. Lying on the floor for a medical examination is something no woman should have to endure! Service providers and medical staff must end their ignorance about the medical needs of disabled women. Disabled women like able-bodied women must have quality health care, this includes family planning information and pelvic examinations that are safe and accessible.

There is an excellent booklet that medical practitioners could use as a resource called, Table Manners: A Guide to the Pelvic Examination for Disabled Women and Health Care Providers. It is published by Sex Education for Disabled People,
Inappropriate health care equipment such as examination tables that cannot accommodate a disabled woman are made doubly dangerous when used by inadequately trained staff. All of these factors result in inadequate health care services for ethno-racial women with disabilities.

4.3.3 Multiple Barriers

Some women were left confused by hostile encounters with health care services and wondered if they were being treated this way because they are disabled or because they are women of colour. Identifying racism is often difficult for women who have multiple barriers in their lives:

"I wonder if they are hostile because I am disabled and causing them extra work, or because I am not white or because my English isn't good and they think I am stupid ..."

“I often find the staff in labs and hospitals to be angry and upset when I ask for accommodation.”

“I can usually manage to take my clothes off in the doctors office, but my hands are quite weak now and I cannot always get them back on. One day at the doctor’s office I had to wait for 45 minutes to get someone to help me get dressed. In the end the nurse was angry and said that this wasn’t her job. I agree with her, so why don’t doctors, especially ones in hospitals provide women with suitable attendant care.”

In these encounters it is necessary to recognize that ethno-racial women with disabilities face multiple barriers, Ethno-racial women with disabilities have unique accommodation needs. They need attendant care, accessible locations, language interpreters and special formats such as Braille, large print and disc or tape. Service providers need to recognize that ethno-racial women with disabilities are one entity, not two or three separate entities (i.e., racial minority, person with disability and woman).²

Many women stated over and over again that professionals need to be educated about the needs of disabled women. For example nurses working in offices that service the health needs of women with disabilities need to be educated about the necessity of providing attendant care. A woman with muscular dystrophy might be able to get her clothes of for the medical exam, but putting a bra back on may be too difficult:

“I sat in an examining room for one hour in a blue hospital gown before someone came to help me. I am also a client and they need to provide attendant care for people who cannot get themselves dressed.”

4.3.4 Ongoing Health Care Maintenance

The problem of women with disabilities getting inadequate health care for their other health issues is a common complaint. One woman noted that she had trouble convincing a doctor to provide her with contraception, because he just could not imagine that a woman with a physical disability would be sexually active.

“I get extremely frustrated sometimes when I go to the doctors. Because I have a physical disability my doctor only wants to focus on my disability. My other health care issues are rendered invisible.”

“I am more than just my disability... I am a whole woman, but sometimes doctors just see DISABILITY and nothing else.”

Other women expressed concern about health issues such as breast cancer:

“... a nurse said to me, when I asked her about breast examinations, ‘Well it's not like your going to get breast cancer too.’ I was very upset.”

One woman spoke of her frustration at getting treatment for pneumonia because the doctor just wanted to focus on her disability.

Another woman who has been deaf since birth noted that doctors always want to look at her ears and that they fail to understand that she is more than her disability:

“There is nothing wrong with my ears, they are not sick!”

4.3.5 Privacy Issues

Privacy in health care and in life is an ongoing struggle for many of the women who participated in the project. Due to their disability many women needed attendant care or ongoing medical attention. Privacy and maintaining privacy in these settings is very difficult, especially when service providers fail to realize that they are treating ethno-racial women with disabilities in a manner that invades their personal sense of privacy and boundaries.

The lack of privacy also translates into a general lack of respect for ethno-racial women with disabilities. The failure to understand privacy needs and provide appropriate accommodations can result in dangerous situations for ethno-racial women with disabilities:
“I was having a routine ultra-sound in a laboratory this year and afterwards I had to use the bathroom. The bathroom, needless to say was not accessible and the attending nurse could not lift me so she brought a man into the facility, at first I thought he was an male attendant. However, when he saw my panties on the floor, he became extremely embarrassed and didn't know what to do ... it turns out this man was just a man the nurse picked out of the people in the waiting room ... consequently I was left in a state of undress with a strange man …”

The violence inherent in this encounter is almost devastating and although the woman was not assaulted she is still coping with the after affect of being humiliated and treated like a non-person. However, this encounter was further exacerbated by the attitude of the attending nurse who told the woman that it was because of her culture that she was upset!

“…when I complained the nurse said, ‘Oh, its just because of your culture, women in your culture are too inhibited, a white woman wouldn't have complained.’ I told her that was not so and I complained to her supervisor, but I don’t think anything was done to reprimand her.”

This situation also illustrates how racism enters into already complex encounters, leaving an ethno-racial woman with a disability uncertain about how to name these interactions.

A visually impaired woman noted privacy was an ongoing issue for her in accessing services:

“I cannot read the health care forms, therefore they must be read out loud to me and a nurse or receptionists takes down my answers. I have had to be quite aggressive in demanding that this be done in a private room as these forms often require intimate personal information, that I do not wish to share with the entire reception area. What really bothers me is the lack of consciousness that the staff had about my right to privacy”

“What annoys me the most is the way some doctors and their staff deal with people with visual impairments. I feel they need to be trained. They are patronizing and make you feel like a child. I have a friend who is visually impaired and has children. When she goes to the doctor with her seven year old the nurse hands the piece of paper listing the next appointment to the child and not to the mother.”

“Yes it’s true, because of my disability I have to see many doctors and undergo lots of different treatments. But, I am still a woman and I am still entitled to privacy. When I am changing, they just stand there and talk to each other acting like I am not there.”
“The last time I went to the doctor’s I was so angry, I had to go to the bathroom but the door wouldn’t shut with my wheelchair in there. I actually had to go to the bathroom with the door wide open!”

The right to privacy and respect is essential to the emotional health and wellbeing of all women. Women who do not have a physical disability may not have to think twice about medical encounters such as the ones listed because they can negotiate their own privacy, they can shut doors, find change rooms, and dress themselves. Women who cannot do these should not be barred from having the same measure of privacy and respect. Ongoing invasions of privacy and lack of respect for a woman’s privacy can result in loss of self-esteem and a myriad of other health issues.

Negotiating privacy within the hospital setting is extremely difficult. Often if hospitals do not have translators present they must rely upon family members to obtain important medical information. This however can also pose a problem in maintaining privacy and confidentiality:

“My mother has no privacy when she goes to the doctors ... sometimes you know you might prefer to have a stranger do the translating for you because you may not want your family to know your problem ...”

Sometimes a woman does not want her family to know the intimate details of her health care problems.

The lack of privacy that ethno-racial women with disabilities encounter in health care settings is related to the notion that women with disabilities as “non-women.” It is in this area that culture, sexuality and stereotypes of disability begin to impact on a women’s life.

4.3.6 Sexuality

Disabled women are often portrayed negatively or portrayed as non-sensual or non-sexual. This results in internalizing the prejudices of ableism. In the article, “Creating Our Own Images,” Shelly Tremain comments on the complex relationship that a woman with disability has with sexuality and feminism. Tremain notes that while feminists demanded that women should not be treated as a sexual object, the implications of this are very different for a disabled woman, “In a sense, to be treated as a sexual object is a ‘privilege’ that nondisabled women have a disabled women do not.” This is an interesting thought and while you may agree or disagree it does begin to highlight the complex nature of sexuality, especially for disabled women. It suggests that sexuality itself is subject constant change depending upon the person’s location. Many ethno-racial women with disabilities wanted to make it fully understood that they are sexual beings, with the same needs and desires as able bodied women.
“I have a right to rear children. This attitude that disabled women should not bear children is linked to the notion that disabled women should not be sexual.”

“I think my doctor is embarrassed that a disabled woman, and a disabled woman from a culture such as mine should be having sex.”

Disabled women are not asexual. Societal attitudes about motherhood make it difficult for disabled women to talk to their health care providers about motherhood.

“When I told my doctor I wanted to become pregnant she said I should consider how much I would be depriving my child of a normal life... this was very upsetting ... I do have a normal life.”

It is important for health care practitioners to check their assumptions about disabled women.

“I find doctors to be very misinformed about disabled women and sex and motherhood and all that stuff ... my doctor many years ago suggested I should get sterilized and told me all kinds of nonsense about not having a child ... I know how to manage my disability and have raised two children both of whom are now grown ...”

Disabled women who are lesbians have noted that their sense of invisibility permeates almost every encounter with service providers:

“One doctor actually suggested that I should seek counseling when I told him I was a lesbian.”

In addition, misperceptions about lesbian sexuality on the part of health care providers can result in inappropriate or inadequate health care:

“My first doctor knew I was a lesbian, so he told me I didn’t have to have regular pelvic examinations ... it wasn’t until I started becoming politicized that I realized that I also need to have them...”

According to Joanne Doucette, in “Lesbians in Canada,” disabled lesbians of colour face triple oppression: “I feel oppressed as a lesbian, but I can’t say it’s separate from being Native or disabled. It all runs together...I find the whole system sucks.”

Disabled lesbians who are also ethno-racial women face constant exclusionary barriers, from mainstream society, the disabled community and the lesbian world:

“...I never see positive representations of myself ... a disabled woman of colour who is a lesbian!”
“Disabled women have stereotyped attitudes, like on my articulation. They can’t believe that a Native person could be so articulate. They say, ‘If I was blind, I wouldn’t know you were a Native woman!”

4.3.7 Racism

Racism is a feature that is present in almost every encounter described so far. Racist stereotypes are used frequently by service providers, drivers and others when they encounter an ethno-racial woman with a disability. Racist stereotypes about ethno-racial women and sexuality are frequently articulated in many aspects of the health care setting:

“I had a doctor tell me that Asian women make good wives.”

“Recently a Wheel-Trans driver asked me if it was true about what they say about women of my culture... it was a very uncomfortable ride.”

“I think that it is because I am Asian as well as disabled that my doctor refuses to talk to me about contraception’s…”

Sometimes a woman might experience racism but find it hard to explain and differentiate between disability and racism. One woman noted that as a Canadian of Caribbean descent she often faced subtle forms of racism in the hospital setting:

“I would go into a hospital, I came from an upper middle class background, my mother was a nurse and father an accountant, I would go to the hospital and had extended coverage. People would automatically think that because you are black that you are from a lower income background and always asked whether I had a family benefit care…”

Sexual harassment and disability has been the subject of a number of reports, yet the violence inherent in these encounters cannot be downplayed. A women alone with a driver, or trapped in a closed office with a health care provider is extremely vulnerable. Ethno-racial women with disabilities who use Wheel-Trans are vulnerable at many levels, often they are alone with drivers for long periods and must be strapped in occasionally by drivers:

“When he [the driver] bent over to put on my seat belt he distinctly touched my breast, I told him off and it stopped, but it reminded me of my own vulnerability in these situations…”

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Inappropriate touching and the potential for violence against women is increased dramatically for ethno-racial women with disabilities.

"I have attendant care and go to many doctor’s appointments and use Wheel-Trans, and in all of these places I am vulnerable to harassment ... it is something I am very aware of…”

For more thoughts on racism please see Appendix C.

Racism is a common thread that runs through many of the encounters that ethno-racial women with disabilities have daily. Racism is not disconnected from the next issue: A lack of awareness on the part of health service providers about cultural issues can also translate into racist incidents.

Many women noted that issues of race and culture were often sources of conflict between them and health service providers. Often it is the perpetuation of negative and racist stereotypes that results in hostile interactions:

“I would like to see sensitivity training for nurses ... they are the ones that I have most of my dealings with and sometimes they are abusive towards me. Saying things like why doesn’t your family look after you?”

“It is really ironic how many people will say to me, ‘Oh you must be so happy to be in Canada ... because in your country disabled people are just thrown out on the street.’”

On top of being racist this statement assumes that a ethno-racial woman is not Canadian. It rests upon the notion that Canadian means white!

“We can be people of colour and Canadian... did they forget this... and furthermore even if I was born elsewhere, I worked here I paid taxes here just like everyone else I am entitled to services!”

The idea that only those born in Canada with a certain skin-colour are entitled to services and health care is racism.

Food and dietary requirements are often an area of conflict between women and providers. Although many services are becoming increasingly educated about food choices and will provide halal meat and vegetarian choices, mainstream services and hospitals are still ignorant about cultural and religious observance of food choices.

“When my mother was hospitalized she was forced to not only eat meat, but also pork, as a result she became very ill and had mouth sores…”

Ethnocentric world views also result in service providers failing to provide adequate food choices:
“...services and hospitals need to receive more education around food choices. I am diabetic and a vegetarian and when I went to see a dietitian the list of food that was given to me had virtually nothing on it that I could eat.”

Appropriate death rites and respect for religious observances was also cited by women as a source of conflict:

“When my mother died we had to fight with the hospital staff about appropriate death rites for my mother.”

Many health care professionals bring racist stereotypes and notions into their interactions with clients and patients from ethno-racial backgrounds.

“I have been using a manual wheelchair for years but my conditions is getting weaker and my doctor was very rude, suggesting that because I live with my family I don’t need or deserve an electric chair.”

“My condition is deteriorating and consequently I had to apply for more attendant care. The worker that I dealt with was very rude and she suggested that I should cut my hair instead of getting more attendant care. I said to her the problem isn’t my hair, its my feet I can’t reach, would you also suggest that I cut off my feet?”

“The last time I went to the hospital for treatment the nurse was very angry when I asked her assistance, she said why didn’t I bring a family member to help me. She said, ‘In your culture don’t family members look after disabled people?’”

While it is true that different cultures care for disabled members differently. It is rude, racist and inequitable to assume that an ethno-racial woman with a disability should be dis-allowed services on the basis of her culture, race or ethnicity. Also assumptions about culture need to be checked by service providers and health care professionals.

“When I go to agencies or attempt to get information on my insurance plan I am often treated like I am asking for a hand out. I worked for many years and am as entitled as anyone to receive my disability pension, but lately I feel like I am asking for a hand out. I can’t help wondering if I would be treated like this if I was white?”

For more information on disability and culture please turn to Appendix D.

4.3.8 Discrimination based upon class and socio-economic status and barriers to education and employment

Health care is not just about getting appropriate and regular medical treatment. Health care is also about whole-life well-being. If a woman is unable to receive education, adequate employment, good daycare for her children her health and well-being will
suffer. Domestic violence, racism and social isolation are also barriers to health. Many ethno-racial women with disabilities named socioeconomic barriers as the biggest obstacle in their lives. Additionally, ethno-racial women with disabilities are disproportionately unemployed. When health care is viewed in a holistic fashion that considers the entire life of a woman it becomes apparent that the daily struggles of ethno-racial women with disabilities can also affect her health.

Many women for whom English is a second language noted that they would like to take ESL classes. However, many of these classes are available only to men or to the breadwinner of the family. Many women noted that if they are fortunate enough to get into an ESL program often the buildings are not accessible:

“ESL classes are difficult to get into and when you finally get into one often the location isn’t accessible.”

Women who spoke English with an accent told of being asked if they need an interpreter:

“More than once someone has said to me do you need an interpreter? I speak perfectly good English, I just have an accent.”

“… a nurse kept asking me over and over if I needed an interpreter, and I said no, I am speaking English … do you need an interpreter?”

“I think that some of the mis-understandings and confrontations that came up in the hospital could have been avoided if there were more people of colour working there … and I don’t mean more janitors.”

“I think that the difficulty in cross-cultural communications in health services is often one of misunderstanding … for example translators in hospitals would be a very important and useful addition. Also having an intermediary present who understood and spoke your own language would make someone feel very comfortable. It is frightening to be undergoing medical procedures and not being able to ask questions or get comfort about them.”

Language barriers are an ongoing barrier for ethno-racial woman with disabilities and their family members:

“A lot of times doctors do not give enough information … and just assume that my father might not understand medical terms. Doctors and health care professionals use language to intimidate us, because they are not willing to spend the time to explain medical issues. Its all ‘word games’ so it is difficult in our culture to as questions because we are supposed to respect people in authority.”
One woman noted that she knew of a woman in the hospital who did not speak or understand English and described the agonizing isolation and lack of emotional support the woman received while undergoing what was supposed to be the healing process. It is important for service providers and other workers to check out their assumptions about ethno-racial women.

“…I feel like they just see my brown skin and decide oh, she's stupid and ignorant.”
“Because English is not my first language I need to have prescriptions and instructions read to me or explained to me very slowly. It’s not that I am stupid but sometimes they make me feel like I am…”

Some women who participated in the focus groups noted that they were aware that they were treated with respect in health care settings. They also noted that often this respect was not accorded other ethno-racial women. This is where issues of accessibility to English and class begins to interact:

“I am educated and aggressive about asking for information. I often get it and I usually get treated with respect by doctors. Other women of colour aren’t. In the hospital I witnessed a very sad situation with a woman of colour and a doctor getting increasingly irate and angry at each other simply because of language. The poor woman was terrified and the doctor was frustrated and it just exacerbated … the whole situation could have been avoided if there had been an interpreter available.”

“I know that the doctor’s treat me with respect because I am educated. I think they end to see me as their equal. But sometimes they let their racism slip and say things like, ‘your not like other East Indians’ … I find this very insulting.”

Doctors need to be aware that ethno-racial women may feel uncomfortable discussing intimate issues of sex and sexuality in their presence. In many cultures and countries throughout the world it is customary for women to be attended to by female doctors and health service workers.

“I would like to ask about contraception, but I am very shy. I can’t ask a male doctor.”

“I waited for many hours in the hospital waiting for a woman doctor. I know the staff was getting angry but I could not see a male doctor.”

Again, however many of these situations require a sensitivity and training that doctors usually do not receive. Some ethno-racial women also spoke of the dilemma of seeing a doctor who was from their culture:

“My doctor is from my culture, I see him in the mosque and one question on the physical is are you sexually active. What should I do?”
“Once I needed a bed pan one night and a male nurse brought it to me, I asked for a female and the nurse returned again to check on me. I was very scared and finally I talked to the head nurse ... I also did not feel comfortable with a male doctor. I have had bad experiences with male doctors. I am also very uncomfortable with male nurses attending female patients in the washroom.”

4.3.9 Socio-Economic Barriers

Many women identified the increasing use of user fees as a barrier to health care. It is a fact that our health care system is becoming a two-tiered one that allows the wealthy to have access to the best medical care. For ethno-racial women with disabilities they are often located on the bottom of the socioeconomic ladder and the use of user fees and pay as you go service is increasingly a barrier to health care.

In addition the cost of mobility devices is increasingly rapidly while insurance companies are becoming more and more fickle about paying benefits and determining eligibility. Many women noted that they need ongoing medical and insurance forms completed by doctors and this is increasingly expensive:

“My doctor charges twenty five dollars for a form … and it may not seem like much but I am on a fixed income and these expenses add up. I just can't afford it.”

“When I registered as legally blind, I had to have a form from CNIB filled out by an eye specialist to prove that I am visually impaired. Not only did it cost thirty dollars but it took a month and several phone calls for my doctor to fill it out.”

“Doctors are not regulated by the government on how much they can charge for signing forms … and when you are on a limited income this becomes a barrier to services.”

The cost of mobility devices means that these aids to living can become luxuries for many women:

“I wonder who is benefiting from the cost of equipment. Why are services and mobility aids so expensive?”

“I was adding up the cost of my chair one day and realized that it is not much less than a small car, for example the frame is $6,000, the seating is $1500, and the foot stand $700 and batteries are $9500. It is outrageous and it is because a few companies have a monopoly. They know we need these and they know that insurance plans or government programs will pay for them.”
Many women indicated that they would like to use alternative and preventative therapies, such as massage and homeopathy. One woman noted that she felt lucky that she could supplement her regular medical therapies with alternative therapies and she noted that many of these actually counteracted the side affect of her regular medications.

“I don’t call them alternative treatments I call them complimentary medicines. If it were not for mainstream medical care, I might not be alive. However, mainstream medicine often has terrible side-effects. Mainstream and complimentary medical care work well together to reduce side effects.”

“I hope that someday OHIP will recognize alternative treatments for billing purposes.”

“I would like to be able to afford some of the alternative treatments but they are too expensive, it’s kind of ironic considering that some of these therapies are older than the ones doctors hand out.”

Socio-economic barriers were increasingly identified by women who participated in the project as the greatest barriers that they faced.

“I am becoming increasingly cognizant of the fact that my worth as a human being is considerably less in the eyes of many because I do not have a job. In this political climate only those disabled women who work are considered worthy of accessing services. For example, my concern is that Wheel-Trans is gradually going to become a service that is accessible only to working people. Just because I don’t work doesn’t mean that I do not contribute to this society. I keep coming up against that notion. You don’t work, therefore you are worthless and can be thrown away.”

“Does getting attendant care have to depend on whether or not you are working.”

“I think that the renewed arguments around Euthanasia are tied to the notion of worth, and increasingly in this society worth is about working at a paid job ... Yet, I do work, I do community work, I volunteer and I live a productive life!”

This is an important question in a society that ties worth to economic status.

Questions about information and access to information were highlighted in a number of discussions. Are people of colour getting the information they need about attendant care?

“I find if very difficult to get information about services and especially attendant care and home-care. I believe that many people colour were not informed.”
4.3.10 Community Action

Are there enough community based groups and services that can provide outreach, advocacy and training?

Many women identified the desire to train, access information and learn job related skills. Women spoke at length of the new economy that is based on computers and technology that should allow disabled women greater access and opportunity. However, getting computers, and information about training is very difficult as services become increasingly fragmented and de-centralized.

“I want to get a computer, because I think that the Internet will allow me to get information about my disability and share my information with others.”

“I know more about my disability than doctors and I would like to find a way to share my information with other women.”

“I am very concerned about the potential loss of rent-control… I fear that I will lose my housing … and I find that community agencies are very uninformed about how to take action or how to organize politically.”

“I feel that by educating all the health care providers that there are people with disabilities that need things such as prescriptions that need to be filled, help with housing etc. Through education a lot of things can be covered like racism, language barriers, attitudes about food, lack of religious understanding etc.”

Women spoke at length about their desire to find fulfilling work and their desire to learn:

“I think that with computers now it might be easier to go to school, my friend is taking a correspondence course and I would like to try that.”

Recent changes to the Canada Pension Plan, and Unemployment Insurance have left many women wondering how these changes will affect them. Again getting information is difficult and time-consuming:

“I spent almost three weeks trying to get through to one agency on the phone….”

Limitations to C.P.P. and rigid definitions of disability disallows women from working part-time:

“I would lose my benefits if I worked part-time, but because of the nature of my disability I cannot work everyday.”

“I am concerned about the deregulation of co-ops and the loss of rent controls.”
4.4 Coping Strategies and Strategies for Change

Although many of the events and incidents that have been recounted are negative it is important to realize that most of the women who participated in the project did not feel angry or depressed. Many women spoke of their own personal strategies for resistance:

“Many of the women that I am friends with also have a disability, we understand what gets us down and can support each other.”

“I used to feel sad and want to cry a lot, but I started to realize the effect that this had on my family and when I stopped I realized that I really liked my life.”

“I have my music and my sense of humor …”

“Spirituality is very important to me.”

Some women spoke of organized religion and family traditions being very important to them, others felt that their own private observances of spirituality helped them. Many women cited religion, prayer, community involvement and spiritual ties as a source of their strength.

“...family, friends, my little pets and religion...”

“I go on my chair in the summer down to the water and just sit there and I am thankful for all the things I do have…”

Very few participants felt that they were powerless and few reported overwhelming feelings of powerlessness. Many women spoke of their resilience and attributed their strength to having to cope with a disability in their lives.

“I know that I have a debilitating illness, but since I have become disabled I have also become a stronger person … I have so much more to offer the world than I did before.”

Many women identified organizations such as Variety Village as being a positive place where they could meet with other women in similar situations:

“I come here weekly and exercise and get together with my friends …”

However some women noted that not all agencies that are designed to be accessible actually are:

“My doctor told me that I should go to the YMCA, but I find it quite frightening there because the corridors are very narrow and the lack of attendant care makes me fear that if I fall no one will help me to get up.”
Day to day negotiations with a disability have forced many women to become politicized and women that were once business women now find themselves doing advocacy work on their own behalf and for others.

One woman who is well known in the community is a virtual resource centre for others, her phone rings day and night with requests for information and advice:

“I do like doing advocacy work for others, it is very fulfilling. However, I would like to see more agencies providing this kind of service. Instead of planning social outings I would like to see agencies hold letter writing campaigns and teach women job skills, resume writing and help them to get computers.”

“…I think that a lot of young women could really benefit from having a place where they could go to be with other women in similar situations and learn and share information and strategies or to get advice…”

How can community agencies provide support for ethno-racial women with disabilities?

“I would like to see a place where I could go and use the computer, especially for resume writing.”

“I wish more agencies would organize outreach programs and help me to meet other women with my disability.”

“Support from other women with disabilities is important.”

“I would like to see agencies and health centers employing women of colour with disabilities...this would set an example and provide role models for young women.”

Many women noted that an agency such as ERDCO can provide much needed information in a system that is rapidly becoming fragmented:

“ERDCO has allowed me to become politically involved and to fight for changes for my community.”

“I would like to see ERDCO or other services or other agencies provide a newsletter of information about women with disabilities, but I would also like to know other people from my religious community as well ...”

“… agencies should get involved in letter writing to protest the cuts that we are facing ...”

Technological advances in communications and computers in recent years have given many ethno-racial women with disabilities hope for future employment.

“If agencies had computers and training programs I would attend.”
“I would like to have a telephone hot-line or service that I could call for up-dated events and information. Why not have a disability line?”

“I would like an organization like ERDCO provide a job bank, or resume writing courses and a centralized location where I could come and access a computer, and other resources.”

4.5 Analysis of Findings

Women who participated in The Women’s Health Project identified barriers to health care that break down into approximately three categories: (1) Physical; (2) Systemic; and (3) Attitudinal.

Ethno-racial women with disabilities face ongoing physical barriers in the management of their day to day life. These barriers may be architectural ones such as inaccessible buildings and health care equipment. Access to transportation that is accessible and affordable was also cited. These barriers often left a woman vulnerable to the problem of systemic and attitudinal barriers.

Systemic barriers include poverty, racism and lack of recognition in health care services of ethno-racial women. Lack of respect in service delivery for a woman’s religious or cultural beliefs and failure to provide for various women’s language needs. Attitudinal barriers include assumptions and the perpetuation of stereotypes about ethno-racial women with disabilities. This includes inappropriate assumptions about sexuality, cultures and values. In addition discrimination based on class status is included here.

4.5.1 Racism

Often a woman will recount an incident yet not name it as racist. Why? The experience of racism is a complicated one for ethno-racial women with disabilities. The experience of racism varies depending upon a woman’s class status, her level of education, her type of disability and her access to employment. Additionally racism is often internalized. We live in a world that tells defines who is ‘normal’ within narrow and rigid boundaries, thus the ethno-racial woman with a disability lives in a world where she rarely sees positive representations of herself or her life.

Occasionally, in the focus groups the discussion would open up and women would cautiously tell of racist incidents. One woman noted that she felt shame and embarrassment about these incidents. Like abuse, racism can become internalized as a source of shame with the result that the woman blames herself. As women who may already be socially isolated the additional burden of racism can be overwhelming.
4.5.2 Racism and Health

Racism causes health problems and is a major source of stress for ethno-racial women with disabilities. It can affect a woman’s self-esteem, and cause anxiety, fear and trigger chronic fatigue in women whose disability left them already vulnerable to such syndromes.

Racism is particularly stressful for women with disabilities because they are already dealing with barriers in our society. Racism is another barrier. The disability movement has not made anti-racism a central part of their working philosophy and consequently, ethno-racial women with disabilities do not have adequate representation in this area of their life.

Ethno-racial women with disabilities not only face racist attitudes from health service workers but also systemic racism in the form of biased immigration codes, ethnocentric medical practices and government funding that give equal priority to ethno-specific agencies and services.

4.5.3 Sexual Assault

According to DAWN Toronto one out of three disabled women in Canada will experience some form of physical or sexual assault. Isolation, poverty, economic dependence, and systemic barriers such as racism make ethno-racial women with disabilities vulnerable to assault.

What we need to ask ourselves is are crisis centres and women’s shelters accessible and are they culturally sensitive to the needs of ethno-racial women? Do ethno-racial women with disabilities have services available to them in crisis situations?

One health care provider stated that it has been a long hard task getting her agency to provide culturally appropriate food and services for ethno-racial women, and when asked if the same agency was accessible she said no.

One service provider stated that a disabled woman that she knew who fled an abusive home had to spend the night on the street in her wheelchair because accessible transportation was not available.

What can be done?

We need more education for workers and service providers and more funding to ensure that shelters are accessible.
4.6 Recommendations

Many of the recommendations that women made revolved around increasing accessibility and service worker education. The discussion about changes revolved around community involvement. Community support groups and peer group support for ethno-racial women with disabilities were identified as essential for women. Specifically, programs such as training and education were targeted as highly important. Access to information and a network or databank that could connect women to other women with a similar disability was also highly recommended.

At the institutional level women were adamant and vocal about change based on education for health service workers, and medical personnel. Knowledge and education for these groups was named as essential in the lives of women. In addition services need to be held in a safe, comfortable and culturally appropriate environment. They also need to take into consideration the health needs, language needs and attendant care for women with disabilities. Receptionists in agencies should inquire about a woman's needs when booking appointments. Consequently, education and training for staff was cited as essential.

Women also noted that the participation of ethno-racial people in agencies and institutions is important in changing societal attitudes about ethno-racial women with disabilities. Also, media representation was considered important to aid in the acknowledgment of ethno-racial women with disabilities as women who are mothers, girlfriends, sisters, friends, and wives.
Section 5 – Part II of Findings: Health Service Providers

5.1 Discussion Guidelines and Questions

Service providers attended two focus groups, the attendees represented a wide cross section of health care agencies.

Discussion questions for the service provider focus groups were based on the following questions:

• How do you define the health needs of ethno-racial women with disabilities?
• How do women presently meet their health needs?
• What support services do women require to ensure that their health needs are met on a day to day basis?
• In your opinion is your organization providing adequate assistance to ethno-racial women with disabilities?
• Do you believe other community agencies are providing adequate support for ethno-racial women with disabilities?
• Are women comfortable in discussing stress related issues with you?
• Do women use or do you suggest alternative health treatments to manage stress?
• Have you witnessed racism in the health care setting towards ethno-racial women with disabilities?
• What are your suggestions and recommendations to provide further support and assistance to ethno-racial women with disabilities?

None of the service providers identified themselves as a woman with a disability. Many of the issues and topics that they discussed highlighted the systemic barriers to health care that they believe women face.

5.2 Findings: Health Service Providers

Health service providers named many of the same issues that ethno-racial women with disabilities named:

• Physical access
• Education and information
• Inadequate training about the health needs of ethno-racial women with disabilities.
• A lack of ethno-specific agencies geared towards the needs of ethno-racial women with disabilities.
• A lack of alternative resources.
• A lack of grassroots health promotion.
• An inadequate amount of available information about cultural issues.
• Privacy as an issue for ethno-racial women with disabilities.
• Racism and oppression in services and individuals.
• Socio-economic biases in the health care system.

Service providers noted that architectural barriers and other barriers relating to general access were a major barrier for their clients who had disabilities:

“I grew up in this culture and even I have difficulty with buildings, especially hospitals. The coloured lines they use as maps in hospitals are incomprehensible. If it were my first experience in Canada it would be overwhelming … hospitals are built like bureaucracies … they are not user friendly.”

“Areas are colour coded, but the signs are in English. They (hospitals) are now thinking of using images for more access. But signs are high and in very small print…”

Service providers also noted that the signage in hospitals and medical buildings are ambiguous:

“Caution automatic doors’…What should I be afraid of? Does this mean doors will open in my face?”

“Why not use x-ray instead of Radiology. Make it plain…”

“Elevators that close too fast are very dangerous for women with disabilities…”

Service providers noted that there is a general lack of education and information about health issues. As service providers, they feel alienated since they are not properly trained on how to accommodate ethno-racial women with disabilities:

“I think that it is important that education be given to health care providers. We need to educate those entering the professions and those practicing. We need to maintain ongoing professional development on both levels.”

Service providers agreed that ethno-racial women with disabilities are less likely to access community health services:

“Ethno-racial women with disabilities do not avail themselves as much as the white population … this has to do with a lack of information and how to get information to those groups …”

Language, ESL and translators were identified as an ongoing barrier for ethno-racial women with disabilities:

“… Language is definitely a barrier, most providers are English speaking …”
“When working with disabled women, there is often a language barrier and a lack of information … it is frustrating …”

“Language and resources are a barrier, not having access to resources in the appropriate language and appropriate format is frustrating …”

Accessing services in English is not the only barrier that service providers identified. They also noted that women who need special accommodation have difficulty:

“Women with Cerebral Palsy have difficulty with language … often service providers do not have the time or do not take the time to understand the woman’s needs …”

“We, as service providers have a responsibility to provide newcomer groups information on health care. For women with disabilities we need to provide them with the appropriate information, however sometimes we also do not have the resources… such as time, booklets, information aids etc.”

“It is true that when we are posting for events we do not think of putting them in large type, or in an appropriate format for the people we are trying to reach . . .”

“Health promotion is traditionally done through producing pamphlets … 90% of them are produced by drug companies … this causes an enormous bias and conflict of interest …”

Racism and lack of awareness around cultural issues were identified as issues by service providers. Racism was identified as a major barrier to health care by service providers:

“I have witnessed staff walking away from clinic reception when they see an African Canadian teenager coming up to the counter.”

“Racism is very subtle and some of it is within the system itself. I would say that systemic barriers are the greatest challenge.”

“I have heard home care workers make very racist comments and when you report these nothing is done … it is just so accepted.”

Many service providers noted that they did not have enough information about dealing with certain cultural issues:

“We are certainly taught in our training that Western medicine is the best way …”

“Asking questions in a respectful and interested manner is really important, often women are very willing to share, yet in our training we are certainly not
encouraged to do this. Yet, in dealing with a woman from another culture, perhaps the only way I can learn is from her ... we have to recognize the expertise of the individual woman.”

“Culture can be a barrier, I have noticed that it is hard to do outreach to women from certain cultures ... because in some cultures you stay home... sometimes the family is a barrier.”

It is true that various cultures treat disability differently, however, instead of trying to force women to adapt to Western methods, service providers could educated in the various ways that they can provide service to women.

Naming culture as a barrier may also be an easy way out for service providers who lack skill in dealing with ethno-racial women with disabilities:

“I agree and disagree about educating the provider about culture. I think it is more important to create an atmosphere that allows the person to share information with the provider, while at the same time, the provider being responsible for asking questions that are not derogatory and that would encourage information sharing.”

“I think we have a lot to learn from the women themselves, they often have expertise and need us to provide resources, skills, training, access and other things ... not to tell them what to do and the best way to do it!”

Privacy is an ongoing issue for ethno-racial women with disabilities. Many service providers noted that this was of concern to them also:

“I have had clients with psychiatric, substance abuse, physical/sexual abuse, and they are very afraid of lack of confidentiality. People want to have their privacy assured, to be sure that family and friends won't know.”

“I know of a young woman who was disrobed and forced to walk around the room so the doctor could view her spinal structure. Her father was present ...”

This is often difficult however if translator services or alternative formats are not available.

“Sometimes a woman does not want to go to get help from within their own cultural community. This is because of privacy issues. Some also don't want us to use a cultural interpreter because they are afraid everyone will know. This is also true of women who are having immigration problems. The answer to this problem is complex ... and requires that we look at alternative ways to service different communities ...”
Culturally appropriate health services are necessary, as well as the availability of female doctors:

“It is difficult for many women to discuss certain issues with male doctors …”

Additionally, ethno-racial women with disabilities need to see themselves reflected in the health care setting:

“Disabled women have another dimension of culture ... they need to be able to talk about this with people who understand what they are experiencing. This is why it is important for agencies and services to do outreach to various communities in hiring, and in getting new board members.”

This issue highlights the importance of having ethno-racial women with disabilities represented in agencies and medical services. It is necessary that women see themselves represented:

“The issue also becomes one of self esteem. Ethno-racial women with disabilities have no role models …”

Class biases and socio-economic barriers were also mentioned by the service providers as a barrier for ethno-racial women who use their services:

“Discrimination is also related to income, if you are poor you get less service. If you are person of colour or you have an accent, you wait longer in the line up.”

“I am concerned sometimes that women are signing consent forms that they do not understand, but they are signing because they are fearful of being denied service.”

“I have heard of service providers in hospitals who assume that because a woman is African and does not speak English they can say whatever they want, however they want to. Ethno-racial women with disabilities face triple oppression in this area...”

There are many ways that we could improve access, beginning with community education and community health services that provide various types of health care in one location:

“Access can be easier. Why can't a person have more than one doctor and all appointments in one place. Services can be compartmentalized.”

“Access is a systemic barrier. Services are not for convenience, but part of an institutions daily operation. Client's needs must be central…”

Many service providers also noted that they themselves lacked sufficient training in dealing with ethno-racial women with disabilities:
“The first time I had to transfer a woman from a chair to an exam table I really had not experience, fortunately the woman herself walked me through it and told me what to do ... I hate to think what could have happened if she did not speak English or was unable to speak ...”

“I had absolutely no training on how to interact with a woman with a disability ... I guess the education I received just assumed that all my patients would be able bodied.”

Many service providers noted they would be happy to see more grassroots health promotion and community organizing for women.

“I would like to see more ethno-specific agencies organizing to helped women advocate on their own behalf...”

“I would my agency to provide advocacy, training, and services in alternative formats...”

Health service providers were generally very educated about the issues that ethno-racial women with disabilities face. They were also very open and honest about their own lack of training and the failures of their agencies to provide adequate accommodation and services for ethno-racial women with disabilities.

More education and training were cited over and over again as an ongoing concern! Service providers were aware that their lack of training in providing health services for ethno-racial women with disabilities drastically affected the quality of health care that they could provide. The number one consequence of this was that ethno-racial women with disabilities faced receiving poorer and less adequate services than other women. This must change.

5.3 Working with Women with Disabilities

Some helpful suggestions when working with ethno-racial women with disabilities by Rafia Haniff, Chair of ERDCO:

- Treat each woman as an individual. Do not stereotype.
- Be respectful of wishes which may seem trivial.
- Do not make assumptions based on physical appearance.
- It is okay to ask questions.
- Listen carefully for replies.
- Form partnerships with community groups that represent ethno-racial communities.
- Be willing to work with family members.
- Be creative and flexible to accommodate culture and disability.
Section 6 – Recommendations

The findings show that ethno-racial women with disabilities encounter multiple barriers when accessing health services. Their experiences not only reveal systemic barriers, but also misconceptions about disability issues on the part of health care professionals.

It is also evident that there is a lack of communication with respect to the dissemination of information about health services and inadequate health education promotion to ethno-racial communities. The alienation and frustration portrayed by the service providers who participated in the study suggests that a great deal of resources (both human and financial) are needed in the areas of health education/promotion and the dissemination of information of health services.

The recommendations proposed in this study are not only implicit in the findings but also represent suggestions made by ethno-racial women with disabilities and service providers. The recommendations fall into the following categories:

6.1 Public Awareness and Health Education

Both service providers and ethno-racial women with disabilities recommended that training programs should be provided for service providers. These programs would include:

- Workshops on cultural diversity
- Workshops on sensitivity to disability and accommodation issues
- Training on how to physically interact with and accommodate ethno-racial women with disabilities.
- Testimonies from women with disabilities about their individual health needs.

In addition to training programs for service providers, participants recommended that information sessions should be held on a regular basis to inform ethno-racial women with disabilities about changes to health care services and other pertinent information. This includes current issues in health education and antiracism issues. The planning of such a program would involve:

- Development of extensive outreach strategies
- Development of alternative publications.
- Informational literature in clear language.
- The use of socio-drama and popular education to stimulate the discussion of issues.
- Steps taken to ensure the safety of ethno-racial women with disabilities.
- The organization of a culturally appropriate retreat for ethno-racial women with disabilities to encourage them to speak openly about the barriers that they face.
6.2 Improvement of the Quality of Service Provision for Ethno-Racial Women with Disabilities

All the participants agreed that the present service provisions for ethno-racial women are inadequate and inaccessible. They recommend that ethno-racial women with disabilities have pro-active roles in the research, development and implementation of services to improve the quality of service provision. This would include:

- Improvement in accessible design in building codes, levered doors, doors that open outwards, Braille in elevators and on pharmacy pricing.
- Inclusion of disabled women on advisory committees.
- Education, public education and media awareness. Broader representation of ethno-racial women with disabilities in advertising.
- Mandatory training programs for service workers, and drivers, and staff. That focuses on how to meet the needs of ethno-racial women with disabilities.
- Improved access to bank machines, rails in washrooms doors that open outwards.
- Resource materials available in offices.
- More focus on wellness and acknowledgment of traditional medicines.
- The use of student nurses to conduct breast examinations for women unable to do this themselves.

6.3 Strategies to Outreach with Ethno-Racial Women with Disabilities

It was acknowledged in this study that it is a challenge to conduct research and recruit ethno-racial women with disabilities. With respect to service provision, it was recommended that innovative strategies be developed. Such strategies include:

- Organizing social events where women could relax in an atmosphere conductive to learning.
- Provide financial compensation to validate women’s contributions.
- Install a telephone newsline for women to obtain information on upcoming events.
- Establish links between women with similar interests to reduce isolation.
- Design a user friendly rescue manual to assist women in accessing health services.

6.4 Access to Quality

Health care services can often be achieved by the removal of financial barriers. It was therefore recommended that a separate medical plan be established to provide medical coverage for women with disabilities. Such a coverage should include:

- Prescription drugs
- Dental services
• Alternative health care treatments
• Massage therapy
• Chiropractic services
• Physiotherapy
• Homeopathy

Ethno-racial women with disabilities are disproportionately unemployed or under-employed and the following recommendations were made:

• Advocacy and outreach to governments and insurance companies to remove marital disincentives.
• Advocacy and outreach to governments and insurance companies to review regulations that disallow disabled women from working part-time
• Training programs that utilize new technologies
• Agencies such as ERDCO to begin job banks and do advocacy on behalf of women who need training, education and computers.
• Encourage secondary and post-secondary institutions to broaden distance education programs geared towards ethno-racial women with disabilities.

6.5 Removal of Physical Barriers

In health services, appropriate accommodation is often overlooked. Hence it was recommended that physical barriers be removed. This would include:

• Provision of sign language interpreters for medical appointments for people who are deaf or hard of hearing.
• Provision for alternative transportation arrangements such as having a chartered bus.
• Provision for the furniture in doctors’ offices to become accessible to people with physical disabilities

6.6 Future Steps for ERDCO

ERDCO is the only organization in Ontario that advocates for the rights of ethno-racial people with disabilities. Advocacy, outreach and education were cited as issues of primary importance to both ethno-racial women with disabilities and service providers. Consequently ERDCO must take a number of steps:

• Publicize the findings of the report
• Continue to gather testimonials from ethno-racial women with disabilities.
• Distribute this report to relevant organizations.
• Advocate for implementation of the recommendations.
• Develop partnerships with other agencies and organizations.
• Produce relevant and appropriate brochures and pamphlets.
• Encourage and initiate leadership roles from ethno-racial women with disabilities, especially in the area of public education.
• Conduct training workshops and advocate on behalf of women who need training and employment education.
• Provide peer support for women and organize mentoring programs.
• Conduct more community consultations such as The Women's Health project.
• Take a proactive stance in the education of home care workers, Wheel-Trans personnel and health service personnel.
Section 7 – Current Literature and Reports

A number of groups in Ontario have produced reports addressing the needs of women of colour and women with disabilities. However, a gap exists in attempting to bring together the unique issues that ethno-racial women with disabilities face and encounter daily. The following list is not a comprehensive or definitive listing of all materials that exist on the experiences of ethno-racial women. At the end of this report is a bibliography that might be useful to researchers, agency workers or women who wish to undertake their own research.

The following literature review is an attempt to locate literature that places women’s health care issues within a broader context. For example within the mainstream medical profession, women's health care issues are often narrowly defined within a framework of personal responsibility. Consequently, the broader connections that exist between socio-economic status and health are often ignored or overlooked. Similarly racism is not conceptualized within mainstream models as violence and is consequently overlooked as a significant factor undermining women’s health and well being. The social barriers that exist to adequate health care are not insurmountable, but they are lodged firmly in place by systemic barriers. The reports, journals, books and other literature represented here recognizes women’s health care as a political issue.

7.1 Literature Review

Hear What We’re Saying: 30 Questions and Answers on Racism and Anti-Racism, Shaheen Ali, explores the issue of racism with psychiatry industry. This work focuses on the experiences of women of colour, refugee and immigrant women who are survivors of the mental health care system.

Women and Disability, by Esther Boylan, published in 1991. This book is part of a series on women and world development. Specifically, it is an examination of how disabled women in various locations in the global context are devalued. This book is about women’s various experiences of disability and contains interviews and case studies. It also addresses the issue of sexuality and marriage for disabled women.

Taking Control of Our Health: An Exploratory Study of the Health Needs of Black Women in Peel, by Sharon Douglas. This report, released in 1994, examines the health care needs of black women in a specific geographical region of Ontario. This project was funded by the Ontario Ministry of Health, Women’s Health Bureau, and represents an important contribution to the literature addressing the specific health care needs of women of colour.

The More We Get Together, edited by Houston Stewart, Beth Percival and Elizabeth R. Epperly is publication that grew out of a 1990 conference of the Canadian
Research institute for the Advancement of Women. This book reprints 22 papers that were presented at the 1990 conference, including pieces about the sexual abuse of women with disabilities and psychiatrization of disabled women. Women who are mothers with disabilities are also represented in this book.

In 1993, Canadian Woman Studies, published an issue called “Women and Disability,” Summer 1993 (Volume 13, Number 4). This issue contains the words, voices, poetry and visual art of over thirty women on the subject of women and disabilities. Of particular interest in this issue includes an article by Lynda Nancoo called “Marriage-able? Cultural perspectives Women with Disabilities of South Asian Origin.” In addition an article entitled “The Disabled Women's Movement, 1983 to 1993” by Pat Israel and Fran Odette, provides a brief overview of disabled women and the women's movement.


7.2 Books about Women with Disabilities

Women with disabilities rarely see themselves represented in a positive and empowering manner in books, film or in the institutions they interact with daily. For ethno-racial women with disabilities this is doubly compounded. In addition to race and disability, their experiences of sexuality and sexual desire are not reflected back in a manner that is positive and affirming. In the words of one woman:

“I feel invisible, I never see myself in books, in movies. I have never seen a disabled woman of colour represented as a sexual being in a movie. Do they think I stopped being a woman just because I am in a wheelchair?”

It is sad to report that there are few existing books on women with disabilities and even fewer on ethno-racial women with disabilities.

The book The Body's Memory has been called “…the first real novel of our movement,” by activist periodical, The Disability Rag. The author of The Body's Memory is a disability activist in the United States and has been arrested several times for civil disobedience. This is her first novel, that chronicles the changing

Across Borders: Women with Disabilities Working Together. Edited by Dianne Driedger, Irene Feika and Eileen Giron Batres. Published by Gynergy Books, 1996. This is a global network of women’s voices that combines stories of personal struggle with poetry as well as political activism.

Pride Against Prejudice: Transforming Attitudes to Disability. By Jenny Morris. Published by New Society Publishers, Philadelphia, PA, 1991. Morris is a disabled feminist and writer who devotes her energies towards writing and advocating on behalf disabled people. This book is a feminist analysis of disability that attempts to break down the attitudinal barriers that exist towards women with disabilities.

Encounters with Strangers: Feminism and Disability. Edited by Jenny Morris. Published by the Women's Press, London, England, 1996. This collection brings together writers, activists and academics in an attempt to explore how feminism can and must acknowledge disabled women. Issues such as motherhood, abortion and the experiences of women of colour are tackled in this volume.

The Rejected Body: Feminist Philosophical Reflections on Disability. By Susan Wendell. Published by Routledge, New York, 1996. Wendell is a Professor of Women's Studies at Simon Fraser University, who became disabled in 1985. In this work she attempts to connect a body of feminist theory to disability issues. She explores cultural attitudes towards the female body and examines this impact upon disability.

7.3 Disability Web Sites

The Internet offers us new tools and new ways to access information. Presently, Internet access is limited to those who have computers, and those who have computers are still a privileged group. However, this is rapidly changing and last year for the first time, computer sales in North America began to overtake television sales. Computer technology is ideal for networking, organizing and accessing information. Disabled women ideally can utilize this as a resource that will not only provide entertainment and information resources, but also as a means of accessible distance education. Many of the women who participated in The Women’s Health project identified the Internet and computers in general as tools they desperately want to have access to! Many younger women hoped to obtain computers to continue their education and to advance their networking and organizational activities. Others spoke of the Internet and email as a means of breaking isolation and reaching out to other women who shared similar disabilities. New technology in the form of computers and Internet access is an important area for service agencies to consider when they are attempting to provide new and up to date information on health services. This new technology can be used to work with us, not against us.
Information changes rapidly on the Internet, but the following websites offer useful and important information for women with disabilities.

The Axis Disability Rights Website - http://www.normemma.com/. This is a Canadian web site that offers information on various issues affecting people with disabilities. This month there was an excellent feature article called “Hell-Bent on Helping,” by Emma Van de Klift and Norman Kunc. This article was originally published in Thousand, J., Villan, R., Neving, A., Creativity and Collaborative Learning: The Practical Guide to Empowering Students and Teachers. Baltimore: Paul Brookes, 1994. This site also contains a wide selection of recommended readings listed according to subject matter, this month featured Disability & Abuse: Euthanasia.

disAbility Information and Resources site is a U.S. based site that lists a number of categories and topics including recreation and travel and conferences that would be of interest to Canadians. This site is at: http://www.makoa.org/index.htm. This is an excellent site that also carries legal documents and links to other newsgroups and mailing lists. You can also enter your own email address to receive notification of changes and updates.

Disabled Peoples' International Home Page is at http://v1.dpi.org/lang-en. This site lists international conference listings and grassroots organizations and makes links to other disability web sites globally.

The Disability Information & Resource Center South Australia at http://www.dircsa.org.au/ . This contains a number of links and information about conferences and other newsgroups.

As a resource, the Internet has almost unlimited information. To harness this information a new magazine called Women'Space is being published by a group of women activists. This magazine is published quarterly by Women'Space, RR #1, Scotsburn, Nova Scotia, BOK 1 RO, Canada. “Women'Space aims to promote accessibility to the Internet, its information, tools and resources; enhance the effectiveness of women’s organizing through national and global connections; bring global on-line resources to local community actions; support the exchange of experiences and ideas amongst women’s groups.”
Bibliography


Appendix A

Ethno-Racial People with Disabilities Coalition of Ontario ERDCO
The Women’s Health Project
Questionnaire
Prepared by Mala Naraine

(1) What is the nature of your disability?
(2) What is your ethnicity and cultural background?
(4) Are you presently employed outside of the home?
(5) Do you live on your own?
(6) Do you live with other people?
(7) What is your marital status? Do you have any dependents?
(8) What level of education have you completed?
(9) How would you define your health needs? What are your present health needs?
(10) How do you ensure that your health needs are met on a day to day basis?
(11) What kinds of assistance or services would allow you greater independence in managing your own health needs?
(12) Are you currently affiliated with community agencies that are relevant to your particular disability?
(13) Are you currently receiving any medical treatment or therapy related to your disability?
(14) Have you considered alternative health treatments such as acupuncture or ayurvedic medicine as an option?
(15) How do you deal with stress in your life? What coping strategies have you developed?
(16) Are you involved in a physical exercise program, physical therapy, chiropractic or massage therapy?
(17) What kinds of barriers have you experienced when accessing health services?
(18) Have you experienced racism when accessing health services?
(19) What kinds of services would help you to accommodate your health needs?
(20) Do you feel that you have adequate access to information on health services?
(21) Do you feel that you were given appropriate information on contraception and reproductive services to make an informed choice?
(22) Have you experienced violations of confidentiality when accessing health services?
(23) Have you experienced any form of harassment when accessing health services?

Comments and suggestions:
What is the name of your organization?
Are the people you represent or support ethno-racial women with disabilities? Please specify.
What kind of health service support do you provide to ethno-racial women with disabilities?
How would you define their health needs?
What are their present health needs?
Do you believe that your organization is providing adequate assistance to ethno-racial women with disabilities so that they could become more assertive about their health needs?
Do you believe that other community agencies are providing adequate support for ethno-racial women with disabilities?
Are the women you support currently receiving any medical treatment or therapy related to their disability?
Have they considered alternative health treatments such as acupuncture or ayurvedic medicine as an option?
Are the women you support comfortable in discussing stress related problems with you?
Are they involved in physical exercise program, physical therapy, chiropractic or massage therapy?
What kinds of barriers have they experienced when accessing health services?
Do you believe that they have experienced racism when accessing health services?
What kinds of services would be best suitable to accommodate the health needs of the women you support?
Do you feel that the women you support have adequate access to information on health services?
Do you feel that you the women you support were given appropriate information on contraception and reproductive services to make an informed choice?
Are violations of confidentiality an issue for the women you support?
Have the women you supported experienced any form of harassment when accessing health services?

Comments and Suggestions