

Ethno-Racial People with Disabilities Coalition of Ontario  
and  
Ontario Women's Health Network

## Ten+ Years Later – We Are Visible...

Ethno-cultural/racialized women with disabilities  
speak out about health care issues

Funding for this publication was provided by the Public Health Agency of Canada. The opinions expressed in this publication are those of the authors and do not necessarily reflect the official views of the Public Health Agency of Canada.

March 2008

## **ACKNOWLEDGMENTS**

**Ten+ Years Later – We Are Visible** wishes to thank the original contributors of the **We Are Visible** project for making visible the issues experienced by ethno-cultural/racialized women living with disabilities.

Without the strength and passion of the women who took time to share their experience and expertise (personally and professionally) by participating in this update of **We Are Visible**, these critical and essential issues would never come to light and the opportunity to address these issues would be lost. Thank you!

Thank you to **Rabia Khedr** for her community outreach, conducting focus groups and key informant interviews and acting as coordination consultant.

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## EXECUTIVE SUMMARY

This project updates the innovative community-based research project, **We are Visible**, conducted in 1996, and highlights the experiences of health and health care of ethno-cultural/racialized women with disabilities in Toronto, Ontario. **Ten+ Years Later – We Are Visible** explores what has changed since the original project, indicating gaps and making recommendations based on our findings that have important implications for current policy development, service provision and research.

Through community-based research and a literature review, this project works to understand the barriers to health and health care that ethno-cultural/racialized women with disabilities face and whether any progress has been made to address the issues discussed by the women in the original **We Are Visible** project. Furthermore, this project seeks to increase understanding of how the intersectionalities of racism, sexism, classism and ableism, coupled with systemic barriers, as experienced by ethnocultural/racialized women with disabilities, impact on women's health.

Analysis of the experiences and perspectives shared with us by ethnocultural/racialized women with disabilities, and by researchers and service providers point to the following key findings:

- **Noticeable decline in the general quality of health care services, including:** 1) increased wait times; 2) delisting of services from OHIP; 3) trouble finding and accessing a family doctor; and, 4) feeling of being rushed at appointments and not listened to.
- **Noted changes that were specific to the participant's understanding of themselves as ethno-cultural/racialized women with disabilities, include:** 1) the feeling of being perceived as a great drain because as women with disabilities, they take too much time from an already strained system; and, 2) that more services are being squeezed into the same amount of space, a particular challenge for women with mobility disabilities.
- **Improvements in the system:** 1) the increase in information and material available on-line; and, 2) that the face of health care has become more diverse.
- **Access to Services:** participants identified numerous barriers that prevented their access to health care services and/or compromised the quality of service they receive: 1) being able to use the

appropriate services as needed and having services financially covered and/or for an affordable fee; 2) having appropriate support from service providers and staff; 3) physical barriers, such as architectural design and inadequate health care equipment; and, 4) transportation and proximity to services.

- **Access to Information:** participants noted the numerous ways they access information as well as the facilitators and barriers to high quality and timely information.

Facilitators to accessing information include: 1) information provided in an appropriate format; and, 2) service providers taking the time to find the appropriate information.

Barriers to accessing information include: 1) inappropriate format; 2) service providers' belief that because the women were disabled the information had to be transferred to a family member rather than directly to the women themselves; 3) information available only in English; and, 4) inaccessible language that makes it difficult to ascertain if the information is accurate.

- **Financial Barriers:** a disproportionately high number of women with disabilities live in poverty and they are facing increasing financial strain and barriers with the increased delisting of services and medication.
- **Providers' Attitudes:** project participants talked at length about the impact of providers' attitudes on the quality of their care and cited the need for training to better equip providers to meet their needs as ethno-cultural/racialized women.
- **Discrimination:** about half of the participants identified experiencing and/or witnessing the discrimination of others in a health care setting.

The specific recommendations of this project include:

- Educate providers in partnership with ethno-cultural/racialized women with disabilities to develop and implement the training. The education would raise awareness on the issues faced by ethno-cultural/racialized women with disabilities as well as provide tools to ensure the developed services and policies meet the diverse needs of women.
- Have representation of ethno-cultural/racialized women with disabilities on the policy and service committees to ensure what is being

developed also draws on the lived-experiences of the women.

- Develop anti-racist/anti-sexist/anti-ableist policies and ensure there are accessible and user-friendly complaint mechanisms developed
- Provide training and information for ethno-cultural/racialized women with disabilities on how they can address the different issues they face at the service and policy levels and fight discrimination proactively.
- Reinstate the services that have been delisted.
- Increase accessibility and availability of services and the information provided.
- Work towards an inclusive society where there is equitable opportunity and access for ethno-cultural/racialized women with disabilities to the social determinants of health with a particular focus on employment, income, housing and lives without violence and abuse.
- Increase number of women doctors.

By addressing the issues for ethnocultural/racialized women with disabilities, particularly around discrimination and access, the environment will improve for many marginalized women who experience similar issues. The findings and recommendations of this project focus on the issues faced by women in Metro Toronto; however, it is our expectation that through our wide dissemination, the project will have broad impacts beyond this community, region and sector.

## OVERVIEW

**Ten+ Years Later – We Are Visible** is the result of a partnership between Ethno-Racial People with Disabilities Coalition of Ontario (ERDCO) and Ontario Women’s Health Network (OWHN). This project consults with ethno-cultural/racialized women with disabilities and service providers to update the **We Are Visible** report that was released by ERDCO in 1996.

Furthermore, this project seeks to understand the current barriers to health and health care that women face. **Ten+ Years Later – We Are Visible** focuses on the social determinants of health, particularly issues of access, which negatively impact the women’s health status.

The Women's Health Project, which generated **We Are Visible**, represented an opportunity for women who face multiple barriers, both physical and systemic, to identify these barriers and discuss the impact that they have on their health and health care. This project was unique because no other study or community consultations at the time had specifically targeted the barriers to health care experienced by ethno-racialized women with disabilities. The major findings of the project revealed that health care is not an isolated aspect of a woman's life; a woman's health and well-being are impacted by many areas of public and private life; and, a woman's access to jobs, training and education are as equally important as her ability to access equitable health services. The project also revealed the innumerable barriers to health care that ethno-racialized women with disabilities face.

Women today continue to face the barriers and challenges described in **We Are Visible**. As such, it is imperative that ethno-cultural/racialized women with disabilities are made visible to service and health care providers, facility planners, policy makers and researchers, and that the issues they face are acknowledged and addressed in a proactive manner. Thus, with **Ten+ Years Later – We Are Visible** as our call to action, we advocate for cross-sectoral networks to incorporate the issues and solutions raised by the project participants. We also encourage increased financial investment to support the development of tools that can be used by Local Health Integrated Networks (LHINs), policy makers (in policy reduction, equity, health care and disabilities) as well as hospitals and other health care facilities, to ensure that awareness is raised and solutions implemented to address the issues faced by ethno-cultural/racialized women.

This report incorporates the voices of the ethno-cultural/racialized women with disabilities, along with those of front-line workers and community-based researchers. The voices of the women who participated in the project are heard throughout this report, with their direct quotations included in **bold font**

It is important to note that there are some limitations to the current report. Some of the issues explored in the initial report are not being addressed in the same detail for this report. This is not necessarily because they are not important and/or because there are not still glaring gaps or significant improvements needed, but rather that based on the data collected, we are unable to make a definitive statement. In the initial report, for example, considerable attention was paid to the issue of the physical accessibility of services. Similar concerns were raised in this project, but not with the same frequency or depth as in the original research. Our analysis is limited in its ability to explain the cause and attribution of this difference. Finally, the participant group for the current report was smaller in size than the original. This is a reflection in part of the smaller scope of the project which limited our time and capacity for community outreach.

## **A. Impetus for this Project**

Over the last decade and a half, there has emerged a growing literature in the health and social sectors emphasizing the significance of the social determinants of health and a mounting call for the need to bring an intersectional analysis to the study of access to health, healthcare and general well-being (Visandjee, 2000; Mulvihill et al, 2001;).

From **We Are Visible: Ten+ Years Later Literature Review**

Findings from the original **We Are Visible** report revealed how the intersectionalities as experienced by ethno-cultural/racialized women with disabilities have a profoundly negative impact on women's health and their experiences of health care. These findings have been substantiated in the decade since the report's publication by the input ERDCO and OWHN have received from members and focus group participants, respectively, as well as through recent research. The lived experiences of women along with the literature demonstrate that ethno-cultural/racialized women with disabilities are increasingly marginalized and made invisible due to the intersectionalities of racism, sexism and ableism. By updating the original **We Are Visible** project, the project partners seek to develop new tools to increase women's visibility and to advocate to and support stakeholders in the enormous task of reducing health inequities.

Currently in Ontario, there are important initiatives related to health inequities and access such as the Toronto Central LHIN Health Equity Plans, the Central, Central West and Central East LHINs Diversity & Inclusion Strategies and the establishment of the Ontario Health Quality

Council. However, these initiatives do not address the issues faced by ethno-cultural/racialized women with disabilities specifically. The project findings reveal that issues raised in the first **We Are Visible** project are still present and in urgent need of attention. If these provincial initiatives acknowledge and address the issues raised in the **We Are Visible** projects, significant ground can be gained and the lives of ethno-cultural/racialized women can improve considerably.

In 1996, **We Are Visible** was a pioneering study on the social determinants of health and the barriers experienced by women who are faced with multiple forms of marginalization. In the decade since, the available literature confirms the link between poverty, race, gender and disability to the systemic barriers to health and healthcare. However, as described in the literature review, there remains a relative deficiency of research, particularly Canadian studies, on the health status of ethno-cultural/racialized women with disabilities:

At most, current research has looked at the intersection of one or two of these indicators; for instance, racialized women and their health status or disabled women and their health status. Very little has been done on the social determinants of health and access to healthcare of women with disabilities from racialized communities (2008).

This project will add significantly to the research landscape and hopefully stimulate further studies that address the issues faced by ethno-cultural/racialized women with disabilities.

With the financial support of the Public Health Agency of Canada, the guidance of our Advisory Committee and the time and experiences shared with us by participants, **Ten+ Years Later – We Are Visible** reveals what has changed and what has stayed the same over the last ten years for ethno-cultural/racialized women with disabilities. These learnings will be brought to the attention of the diverse sectors, including service provision and policy development, where equity initiatives will make a positive difference in the lives of women. Our hope is that these opportunities for change will not be lost and that the issues ethno-cultural/racialized women with disabilities experience will become visible.

## **B. Background of Partners**

ERDCO 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 inclusion of ethno-cultural/racialized 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-cultural/racialized people with disabilities of all ages, racial, cultural, linguistic and religious backgrounds.

OWHN is a network of individuals and organizations that promotes women's health. OWHN works with women, health and social service providers, community organizations and others to support equitable, accessible and effective health services for all women in Ontario. OWHN's mission is to link women to health information and resources; and to address the health and healthcare barriers faced by women in Ontario, particularly women who are marginalized, through our community-based research and advocacy work. OWHN's vision is a society in which every woman is provided with the opportunity to achieve, sustain and maintain health as defined by the woman herself, to her full potential.

The project Advisory Committee is composed of ethno-cultural/racialized women with disabilities, community-based researchers, health service providers and an academic partner.

## **C. Methodology and Activities**

**Ten+ Years Later – We Are Visible** used grassroots participatory research to document qualitative data as well as a literature review to establish a scan of the research conducted since **We Are Visible** was published in 1996. This report is grounded in the voices of ethno-cultural/racialized women with disabilities, front-line workers and community-based researchers. Data was collected through the use of focus groups, questionnaires, key informant interviews, a community consultation and demographics.

**Ten+ Years Later – We Are Visible** completed:

- three focus groups (two in-person and one by telephone)
- eight telephone interviews
- one questionnaire completed by email
- four key informant interviews with front-line workers/researchers
- one community consultation
- a literature review

Women were invited to participate in the project through word of mouth outreach and the circulation of a notice on the ERDCO listserv and among community partners. Front-line workers and researchers were also sought through word of mouth and promotion on the ERDCO listserv as well as direct contact with individuals.

A glossary of terms was shared with participants to ensure there was an understanding of the language being used for this project (see Appendix A). ASL interpretation was available as required and no other requests were made for translation services. The questionnaire (see Appendix B) informed the questions asked in the focus groups, telephone interviews and key informant interviews. The community consultation was a two hour meeting held with participants from the focus groups and interviews along with key informants, including service providers and academics. Preliminary findings were presented and participants' comments, reactions and experiences were sought.

## **D. Who we spoke to**

**“My health is very good except there is not an interpreter available.”**

**Ten+ Years Later – We Are Visible** consulted with 20 ethno-cultural/racialized women with disabilities living in Toronto and four front-line workers and community-based researchers. Most of the women were between the ages of 25-54 with a few being younger and a few older. The majority of the women were Canadian Citizens who have lived in Canada for 10 to 25 years. They represent diverse ethno-cultural/racialized communities and identified as African, black, Caribbean, East Asian, Latin American, Middle Eastern, South Asian and Southeast Asian. A majority of the women did not have English as a first language.

According to the 12 demographic sheets that were returned by the project participants, the majority of the women rate their health as fair and the majority requires extra support, relying on their families quite heavily. Most of the women indicated that they experience physical/mobility or sensory disabilities and a couple identified as having multiple disabilities. Even though most of the women have received at least some postsecondary education, many are still living at or below the poverty line. According to the demographic responses, most of the participants rely on government assistance such as the Ontario Disability Support Program (ODSP) or Canada Pension Plan (CPP).

## **E. Definition of Terms**

When the initial **We Are Visible** report was released, we used the term "ethno-racial women with disabilities." Since then, however, there has been a shift in language and the appropriate term is "ethno-cultural/racialized women with disabilities." This shift in language is based on a greater understanding, both in the literature and from women's lived experiences, that the issues they face based on culture and race are systemic in nature and result in discrimination. That is to say, we wanted to draw attention to the fact that discrimination is a result of systemic biases, as opposed to being about the race and culture of the women themselves. The word "racialized" points to prejudices experienced due to race, and better represents the issues we are trying to communicate as opposed to "ethno-racial."

## **F. Statistical Community Overview**

**Ten+ Years Later – We Are Visible** focuses on ethno-cultural/racialized women with disabilities who live within the Metro Toronto area. Determining the demographic statistics of this "community", however, is challenging given the lack of statistical analysis that undertakes the intersection of disability with ethno-racial status. Surveys are available that examine disability on the basis of gender, but it is rare to see statistics on the numbers of racialized people with disabilities, let alone the numbers of racialized women. This gap in information speaks to the importance of our work to increase the visibility of ethno-cultural/racialized women with disabilities.

What follows are statistics on disability and gender in Canada and the province of Ontario and some numbers on the financial status of women with disabilities. According to the 2006 Statistics Canada Participation and Activity Limitations Survey (PALS), 4.4 million Canadians living in households reported having activity limitations, which translates into a disability rate of 14.3 percent. Ontario's disability rate is just over this national average at 15.5 percent, or 1,853,570 Ontarians (Statistics Canada, 2006). While there are no specific statistics, it can be assumed that a considerable percentage of this population includes ethno-racial people with disabilities.

The PALS also indicates that Canadian women, 15 year of age and older, experience a higher prevalence of disability at 15.2 percent, than Canadian men at 13.4 percent. In 2006, 19.5 percent of Ontario adult women reported

having a disability compared with 16.6 percent of men (Statistics Canada, 2006). Women with disabilities are significantly more likely to experience abuse than non-disabled women. It is estimated that women with disabilities are 1.5 to 10 times more likely to experience violence than non-disabled women, depending on whether they are living in the community or an institution (Public Health Agency of Canada, online)

Women with disabilities are more likely than non-disabled women to be unemployed and reliant on government assistance and are among the poorest members of society (National Clearinghouse on Family Violence, 2000). According to a recent report funded by Status of Women Canada, which cited 2002 Human Resources and Skills Development Canada statistics, 25 percent of people living in low-income households are people with disabilities. Of working age adults (aged 16-64) with disabilities, 48 percent were dependent on governmental programs as their major source of income (Stienstra et al., 2004). The report further indicated that women with disabilities are three times more likely to be reliant on government assistance than women without disabilities and more likely than men with disabilities (Stienstra et al., 2004). Canadians with disabilities who receive social assistance still live below the poverty line in every province and territory, a reality that has not changed in the decade since the original **We Are Visible** report was published. However, some improvement is indicated in PALS on the participation of women with disabilities in the workforce. The 2006 survey indicates that 53.4 percent of women with disabilities in Canada had some level of employment, an increase of 14.4 percent from 2001 (Statistics Canada, 2006).

## KEY FINDINGS

When the first **We Are Visible** report was released, the project was at the forefront of research exploring and explaining the intersection between race, gender, class and disability. This project described the importance and the impact of this intersection on women's lives. Over the last 10 years, an understanding of this intersection has increased. However, this increased understanding has not led to corresponding changes in how we develop policy, conduct research or provide services to ethno-cultural/racialized women with disabilities. While there have been some changes in the issues raised in the original report, few of these changes have resulted in improvements in the health status of ethno-cultural/racialized women with disabilities. Indeed, many changes that have occurred have resulted in a reduction in women's quality of life. Thus, the challenge now is to ensure our understandings of the issues are reflected in the policies and services that are provided as well as in the research that is conducted.

**Ten+ Years Later – We Are Visible** hopes to make these issues visible, again, and to collaborate with the appropriate sectors in order to develop tools to apply this understanding in meaningful and relevant ways.

The key findings of **Ten+ Years Later – We Are Visible** include:

1. Changes in the past 10 years
  - Noticeable decline in services
  - Changes specific to participants' experiences of intersectionality
  - Improvements in the system
2. Discrimination
  - Naming and challenging discrimination
3. Access
  - Access to services
  - Access to information
4. Financial Barriers
5. Providers' Attitudes

## 1. Changes in the past 10 years

### ➤ Noticeable decline in services

Most of the women who participated in **Ten+ Years Later – We Are Visible** indicated that they have noticed changes over the past 10 years in the accessibility and availability of services; however, the changes they identified were about the general quality of health care services. When they were asked specifically about changes in services as they experience them as ethno-cultural/racialized women with disabilities, the majority of the women noted no changes.

There was a strong feeling amongst participants that health care services are in decline. The women of the project shared concerns about health care similar to those of non-disabled, non-ethno-cultural/racialized members of the public. Additionally, many of these concerns are about the same areas of health care service that women had expressed concern about in the original project.

Declines in service were noted in these areas:

- Increased wait times

**“Waiting period walk in clinic etc. they give me an appointment sometimes I have to wait for hours and can not see the doctor right away they refer me to another time...”**

**“More crowd, waiting periods its rush rush rush the hospitals are the same if you want to do an MRI its so slow moving everything.”**

- Delisting of services from OHIP

**“Physiotherapy used to be available for me without payment and now it’s a big payment chiropractor the same certain prescriptions the same etc.”**

**“Yah, the home service – she use to iron my children’s clothes, vacuuming and laundry – like she comes twice now none.”**

**“With homecare cut backs are there. I just have to go with the flow and work with the hours I get and thank Allah that I have my family supports network in place. I am glad I have**

**something to fall back on when my supports were cut back!”**

**“As services are downgraded women with disabilities are increasingly left without resources. Attendant care services are stretched to the limit and women are finding it increasingly difficult to access the attendant care they need to maintain independent lives. With shorter and shorter hospital stays becoming the norm and with people being discharged quicker and sicker the strain on available homecare is becoming intolerable. And who is providing the homecare? I know that in Toronto [it] is increasingly, ethnoracial immigrant and refugee women. These women are paid barely more than minimum wage; they are forced to travel from home to home throughout the city; they risk injuring themselves due to the heavy demands of the job.”**

[Front-line worker]

- Trouble finding and accessing a family doctor

**“Getting a family doctor I find they are more selective where else before there were always doctors.”**

- Feeling of being rushed at appointments and not listened to

**“Walk in clinic I am finding too much of a rush to get to me and there is not a willingness to sit and listen to me and I have come from appointments feeling my concerns were not noted with consideration there is rush, rush...my issue is please listen to what I am saying and please don't see as if I am wasting your time...”**

**“Wait for an hour at a minimum and then see the doctor for 10 minutes and creates the atmosphere for rushing because I feel like I am holding up the line.”**

### **- Changes specific to participants' experiences of intersectionality**

...individuals with disabilities are impacted not simply by their respective impairments, but by various factors that intersect and interplay separately and together to create diverse and unique experiences within society. Issues such as one's gender, sexual orientation, race, class, immigration status etc, work in conjunction and impact upon one another

in ways that at times may be very difficult for an individual to articulate (OHRC, 2001).

From **We Are Visible: 10+ Years** Literature Review

It is important to note that when women were sharing their experiences, it was not always possible for women to know whether an experience of discrimination resulted from one aspect of their identity, or an intersection of them. In light of this, it is challenging – perhaps not possible or advisable – to write about the impact of discrimination without focusing on multiple aspects of women’s identities.

Changes noted that were specific to the participant’s understanding of themselves as ethno-cultural/racialized women with disabilities, include:

- The feeling of being perceived as a great drain because as women with disabilities, they take too much time from an already strained system

**“Getting steadily worse over time because the offices are more crowded and the staff seem to care less. Feeling that the more times I turn up at emergency for the same kind of complaint I become less important, I am more of a nuisance and I feel very emotional. I try my best not to need them. I stay home from work when I have more pain, it’s easier to just stay home don’t seek help.”**

- That more services are being squeezed into the same amount of space – this is particularly challenging for women with mobility disabilities who rely on wheelchairs

**“The clinic used to be wider and now shrinking whether the clinic or the doctor’s office.”**

**“I was doing an MRI for my daughter and I was told to sit at a place like you know as if because of my disability and again I go back to the fact that I couldn’t use my wheel chair in this little places right...she wanted me to sit in that place maybe she was worried that I would fall down or something and I felt I was deprived of being a mother and if there was another mother with her daughter in there I don’t think she would have asked her the same way or she would have told her where to sit. I felt at that time she is really doing this because of my disability.”**

## ➤ **Improvements in the system**

The women who participated in **Ten+ Years Later: We Are Visible** identified a small number of improvements in the system over the last ten years. These improvements include the increase of information and material available on-line and that the face of health care has become more diverse. Unfortunately, however, these changes are not enough to fill the enormous gaps still present in health care delivery for ethno-cultural/racialized women with disabilities.

**“Positive there are more things on line and I only lost my vision 2.5 years as visually impaired its apparently more difficult...there is usually numbers on the computer that really don’t answer my questions when I call them.”**

**“There is still a lot of ignorance but I do see some improvements in the works. And it’s no longer the little white nurse all the time it’s more multicultural nurses.”**

## **2. Discrimination**

**“Racism causes health problems and is a major source of stress for ethno-racial women with disabilities. Like abuse, racism can be internalized as a source of shame with the result that the woman blames herself. As women with disabilities might already be socially isolated, the additional burden of racism can be overwhelming.”** [Front-line worker]

About half of the participants identified experiencing and/or witnessing the discrimination of others in a health care setting. Initially, many of the women had difficulty discussing personal experiences of discrimination, but as the questions progressed, these issues were increasingly raised by participants. Discrimination could be in the form of ablism, racism, sexism, classism or the intersection of any combination of these and other ‘isms’.

**“I guess sometimes the intentions are good but they don’t know how to handle people with disability because when my father or my mother were in the hospital for years the blind woman taking her parents to the emergency... and they don’t know how to deal with a blind person it’s a new environment. I don’t see anything I think their intention is good but they don’t know how to communicate you know what I mean? I don’t**

**think they treat you differently because you are a minority.”**

**“Been drawn to tears at emergency and doctors office although the doctor is kindly and he is white Canadian the staff at the front who are multicultural they treat me differently as if they value others over me. Shouting, not explaining well enough and then they embarrass me. When one is sick one is vulnerable and they are not kind and instead they shout harsh words and intimidate me”**

**“I have heard under their breath people talking about other people, they come here to access the Canadian services and that’s why they are being deprived because of these immigrants.”**

**“....Some people react because they don’t really want to help. Whatever they feel they have to do extra work, mostly when they have tasks or some things.... Sometime I notice sometime they ask where are you from which I don’t think it’s needed. Sometime ask are you [from] Iran? Are you Sikh? Are you Muslim? I don’t think those questions are related to your health or how it’s relative.”**

**“That I am a nuisance to the system. I perceive that because I don’t look a certain way I will not be taken seriously. Difficult to prove it but I perceive it. Because some people might consider me light skinned and light brown hair and eyes as fortunate it has been funny how people quickly change their pleasant smiles and attitude the minute they hear my accent. I also know the minute the receptionists look at my file, their attitudes change. Also I am also afraid of the emergency department at the hospitals. The notion that because one is disabled then it’s their lot in life to persevere with the pain is evident in the emergency staff.”**

**“Accent, disability. I have always been an assertive woman so hasn’t experienced gender biases. Skin color and accent don’t seem to match, they think I am French Canadian and when they realize I am not, the level changes to downward respect. Immigrants are a burden to society and they just want attention.”**

**“Physical disability because I fall and people think I am drunk as opposed to being handicapped.”**

**“Yes often dismissed, by uncaring health professionals – not valued due to their disability. Viewed that they wouldn’t understand anyways. Mental health services are never offered to people with intellectual disabilities because people do not understand how to serve this community. Racism is a reality in the health world – but in some research we did, we found that ethnoracial people with disabilities felt that the discrimination that they experienced was based more on their disability than their race.” [Researcher]**

**“The system is extremely depressing. I throw my hands up and I am fed up and I am prepared to do something and not alone. I feel I am participating in eradicating the above and I feel this is a step in the right direction for me. It is possible that I am discriminated in ways even I don’t understand and I sacrifice my self esteem to get help sometimes. Also the comment of hearing about those immigrants who are here to drain our health system and abuse it is very degrading.”**

The experience of discrimination has a negative impact on the lives of ethno-cultural/racialized women with disabilities. It can affect a woman's self-esteem, cause anxiety, fear and trigger chronic fatigue in women whose disability has left them already vulnerable to such syndromes (ERDCO, 1996).

While many of the women experienced discrimination in a health care setting, none of the women interviewed were aware of these service agencies have policies that promote equity, anti-racism/anti-oppression and diversity. It is inferred from the women’s comments that when service providers are not trained, they resort to their own judgment which is informed and grounded in the systemic discrimination in our society.

**“There is a lack of training and they [professionals] use their own judgment. There is no process and no awareness. I think if you are a minority group and one has disability, instinctively one is treated differently and it’s a fact.”**

**“A lack of awareness on the part of health service providers about cultural issues can translate into racist incidents. Women’s responses to such incidents are often hidden under various protective layers that they have adopted as coping**

**strategies. That is, issues of racism hide behind disability issues. Coping with a disability takes up time and energy; women are often experiencing fatigue and pain. When they are confronted with racism it is too much to deal with and it is sublimated.”** *[Front-line worker]*

➤ **Naming and challenging discrimination**

There were few instances where ethno-cultural/racialized women with disabilities were able to address the discrimination they had experienced. Below, the women explain in their own words the intense fear of challenging professionals’ behaviour and clearly illustrate their feelings of powerlessness.

**“I have never attempted to correct any of the perceived or otherwise notions of different treatment for me and I sometimes needed to change the location and practitioner but since that was not in my power, I ignored it.”**

**“Did not feel brave or bold as I was already vulnerable and I felt too affected and not have a forum or anyone who advocated for me and that’s why I am doing this survey. I was too broken and went away.”**

**“I never told the story because I was helpless in hospital and I was scared they would do bad things but I told everyone that I met from the community because I wanted people to be aware of these issues.”**

**“I find honestly when I am caught in a situation and I am faced with I can feel like its too much and I get in the emotion of it I just feel so down and so sad I want to do the right thing and I am not able to and because I am so overwhelmed with all these feelings, that I am not going to do I don’t feel its in my mind to correct them at that point because I am just trying to handle the situation and get by and I think they really need to be more prepared to handle these situation. I think its as much on me because I didn’t bring it up than on them because they didn’t see it to prepare themselves to handle some situations.”**

**“...when I didn’t feel comfortable with my first family doctor, I changed because I felt I didn’t belong there. My accent also is a major deterrent as people treat me differently because of it. My**

**background and the country I come from, I feel makes people treat me differently also."**

Some women felt their experience made them better able to challenge the discrimination.

**"I think my disability made me more outspoken and so I always correct them politely."**

### **3. Access**

As in 1996, accessibility remains a pressing issue for the participants. For this report, the issue of access is divided into two areas: 1) the accessibility and availability of appropriate services; and 2) the accessibility and availability of appropriate information.

#### **➤ Access to services**

**"Yes, I need personal care which does not meet my needs. I need three times a week so it's not enough. I have a lot of problems when I go in doctor's offices. The tables are not comfortable and are very narrow and it's very hard to lie down on that."**

Participants identified many services that would improve their quality of life which are currently not available or are inaccessible. Yet today, as in 1996, even where services are available, they are often met with other barriers such as location, accessibility of the building, level of cultural appropriateness, financial barriers and amount of paper work.

Being able to use the appropriate service when needed and have it financially covered and/or available at an affordable fee means the difference for many women between having and not having access to health care services.

**"... so I get referral, physiotherapy is not covered and if you are limited by private insurance then you are really limited."**

**"A lot of things are not covered, they cover what they want which is not in my advantage..."**

**"They don't provide a service as before. They only help with your bathing and your bed. They don't provide any other**

**service. They say these are government cuts but people really need help. So you're not given the services you need no. I ask so many times but they say they only provide bed and bathing because of government cuts."**

**"The paper work is quite complicated and unrealistic, get a note from this doctor and that doctor, and this doctor is running around and it takes forever and it makes it impossible, lack of transportation to help me accomplish these things, lack of funds"**

Receiving appropriate support from service providers and staff also makes a difference in a women's access to services.

**"I do have all the home care I need and I have had services since 1998 and they are very good at maintaining my services and maintaining consistency with my PSW and they always send someone I have had before whether its recent or the past. I am aware of the services and I know how to access them."**

**"Family doctor gives all resources in terms of specialists and refers me only to doctors in the downtown because the doctor knows my limit and tries her best to accommodate me in the areas she can."**

In 1996, women indicated that there were physical barriers such as architectural design and inadequate health care equipment that limited their access to health services. Today, these physical barriers continue to compromise women's access.

**"They shrink the doctor clinic and adding more rooms and there is no way I can get in with my wheelchair at the doctors office and I don't go just for me which makes it more difficult for me as I take care of my kids and I have to walk with my crutches and guide my little one even the walk-in clinic not just my doctors clinic but her space is really bad space wise and I wanted to ask if she has other people with disability as patients and the walk in is the same and I can't move around there without making a scene asking people to move and accommodate me, its quite a challenge I push myself and use the crutches and its hard in**

**the winter time because of the floors and I am afraid I might slide so I am taking a risk.”**

**“The tables are very hard to get up on. I find it very difficult. People didn’t believe me when I said I was disabled until I had trouble walking.”**

**“It’s kind of hard when you have a physical disability. I can’t climb the table. Now the hospital has lift to make it easier. I’m paralyzed from shoulder to toe. To book for a specialist you have to wait to book for a long time.”**

**“With MRI’s I did have a problem getting an appointment because I need help to have somebody help me get to the room.”**

**“Since I am in a wheelchair, if I have to go for a test like ultrasound where I have to transfer and everything, it becomes an issue and I have to take someone with me to transfer because usually they don’t have someone to help me transfer. It’s more about mobility than anything else.”**

Transportation, another major barrier identified in the original **We Are Visible** report also continues to impact women’s health care access. Participants referred to transportation and their own proximity to services as either facilitators or barriers.

**“I live in downtown area hospitals and clinics are fairly accessible in terms of public transport.”**

**“I found out about this service in my neighbourhood and they cost half the price of a taxi.”**

**“Getting a family doctor is an issue and there is no walk in clinic in close proximity. There is a presumption that people can afford taxis all the time and it’s a \$40 round trip if I don’t take the bus.”**

**“Like they say Wheel Trans is not good for blind people but if the weather is bad then or if I am going to a strange place I need that service they should put this into consideration and I need a safer and comfortable transportation to go there.”**

**“Distance and travel are also problematic due to reliance on the uncertain services provided by Wheel Trans.”** [Front-line worker]

➤ **Access to information**

**“I can’t navigate the system.”**

Project participants noted numerous ways that they gathered information such as via the internet, local community services and their health care practitioners.

**“Web information, library information, and general information from referring. Once in a while through the library but majority of the time on line at the local community centre.”**

The women identified facilitators and barriers in the ability to access high quality and timely information. Women who understand English experienced fewer challenges navigating the information sources, however even where the language was not a barrier for them, women often found that the material was not presented in an accessible manner that considers their disability, i.e. visual impairment.

**Facilitators to accessing information include:**

- information provided in an appropriate format, such as audio books for those who have a visual impairment, and service providers such as a doctor, librarian, community and front-line worker taking the time to find the appropriate information.

**“I read lots of books on health, through CNIB audio books”**

**“I ask the doctor. Sometimes the questions get answered sometimes they don’t.”**

**“Before when I had a fracture and I was in bed I had community care access service workers and they were very good to me in providing all information.”**

## **Barriers to accessing information include:**

- Inappropriate format which impacts the availability, quality and the timeliness of the information. As well, when the information is not in an appropriate format it compromises the women's confidentiality and creates a dependency on others which is not appreciated.

**"Being visually impaired there isn't much there and if it is, it is dated and one doesn't get up-to-date information ... and not available in alternate format."**

**"If one is visually impaired there is nothing out there I don't have anything in the format I can read and sometimes it's confidential and I don't want people to see it like filling out forms and I don't feel comfortable sometimes. My privacy is violated because I am meeting a stranger and it's hard to explain but I have no other choice if you don't have a family you have to rely on those people."**

**"not being able to see there is a lot of written information that I can't read example of a diabetic meal plan I could not find that anywhere on any website and I had to pay for it and I had to call the diabetic association who didn't have an answer and sent me something that I didn't need."**

- Service providers' belief that because the women were disabled the information had to be transferred to a family member rather than directly to the women themselves.

**"Information gets filtered by the relatives or nurses and if I can't see it...I feel like I missed part of it."**

**"I corrected the person who was addressing my sister and I stated that I was able to talk about my own issues in a nice way."**

- Information available only in English

**"People who have second language from other countries have problems to call and to talk."**

**"I don't understand the language, I just answer yes or no. I can't read the face."**

**“I get information from the doctor. I don’t understand the internet because my English is very poor.”**

- Inaccessible language that makes it difficult to ascertain if the information is accurate

**“Have to search a lot and make sure the source is valid and providing enough. The information is scattered and its time consuming to find accurate information of what I am looking for in the internet. Some of the flyers use language that is difficult to comprehend.”**

**“I am not comfortable with the internet and sometimes the explanations are too lengthy, I find the information not too straight forward. The flyers are usually more straightforward although sometimes the words on the flyers are too medical and makes me look in the internet to find out the meaning of the work.”**

#### **4. Financial Barriers**

**“Financial – people with disabilities are poor and the racialization of poverty is a well known fact now, so women are at a triple disadvantage.”** [Front-line worker]

As the statistical analysis above demonstrates, a disproportionately high number of women with disabilities live in poverty. This has not changed since the **We Are Visible** report was published in 1996. With the increased delisting of services and medication, ethno-cultural/racialized women with disabilities are facing increased financial strain and barriers.

**“For the first time last time the meds that they prescribed was not covered and since it was a very high dosage, it cost 200+ and I had to pay for it myself and most of the time its covered. I find being disabled sometimes things are not covered by my benefits and like I wear support stockings and the price is usually very high. The range for it is about 80+. For instance also for immunity inoculation ODSP doesn’t cover but then they refer you to Ontario Works.”**

## **5. Providers' Attitudes**

The project participants talked at length about the impact of providers' attitudes on the quality of their care and cited the need for training to better equip providers to meet their needs as ethno-cultural/racialized women.

**"Yes a lot. Yes, no doubt. Some of those barriers are related to physical access and attitudinal issues and culture. There are some places to some people act like they never saw the person on wheelchair. Maybe, they have no clue how to service."**

**"I feel dismissed and has been disabled for 12 and 13 years and came to this country as a disabled person. I was in a car accident 6 months ago which made things worse. Found that I am usually told, "Well, if you have this condition what do you expect? Take pain killers." I feel that the medical staff should take their time to find what else went wrong with my body and stop focusing on my disability. I'm sick and tired of the attitude I face and especially when my x-rays don't reveal anything and the staff think I am draining this country's resources by demanding for medical attention that I don't need."**

## RECOMMENDATIONS

**“I would like to see the results of our research publicly available to clinics and hand it to new comers and the Ministry. There is a website called Access Ontario, lots of newcomers use this website and would like to see this kind of data available to them.”**

The recommendations gathered from **Ten+ Years Later – We Are Visible** are consistent with those made in 1996 and draw on the lived experiences of ethno-cultural/racialized women with disabilities, addressing the issues that they face based on gender, race and disability, and on other social determinants of health. Some of the recommendations incorporate multiple aspects of their identities and others draw more predominately from one aspect.

The implementation of these recommendations will enhance 'The Aging at Home Strategy', the policy work on equity and the initiatives being developed at the LHIN's and other health equity initiatives being under taken in the province. In addition, the work being done by the province regarding disability must incorporate the learnings and recommendations of this project to ensure that ethno-cultural/racialized women with disabilities are visible. As one woman noted, if we don't make these changes:

**“...they will do this over and over and people are going to be caught at vulnerable moments when they can't speak up for themselves for one reason or another and they are going to be enduring this.”**

The recommendations are:

- Educate providers in partnership with ethno-cultural/racialized women with disabilities to develop and implement the training. The education would raise awareness on the issues faced by ethno-cultural/racialized women with disabilities as well as provide tools to ensure the services and policies developed meet the diverse needs of women.

**“Took the opportunity to teach them about my condition so that they are able to be more sensitive to the next blind person they see!”**

**“Maybe have things like workshops for awareness on people with disability as far as health services.”**

**“We need to improve. I think they need more training. They need sensitivity training and I think also they need more advocate rights and should have other choices for the tests, know how to accommodate you. They need something on how to improve their attitude... More information on how to fight discrimination.”**

**“I believe that we must pay particular attention to the triple barriers of ableism, racism and sexism. As service providers, it is our responsibility to educate ourselves about issues of race, culture and disability in order to provide appropriate services for everyone. Together we must advocate for the integration of ethnoracial people with disabilities into all aspects of society. Justice is not justice unless it is for everyone.”** [Front-line worker]

- Have representation of ethno-cultural/racialized women with disabilities on the policy and service committees to ensure what is being developed draws on the lived-experience of women.

**“When making policies they should have someone on their council who is representing someone who is representative of the community of disabled people so they get a real sense of the different experiences that people experience and not just themselves.”**

**“They don’t know how a blind person feels so there should be representation...”**

- Develop anti-racist/anti-sexist/anti-ableist policies and ensure there are accessible and user-friendly complaint mechanisms developed

**“I should have gone back and complained and educated them and open their eyes...”**

**“Well, I would really recommend that this report and recommendations that you are making should include that it becomes mandatory for health care workers to do some studies on racial biases in the health care system; it is pretty simple and can make a world of difference.”**

**“Sensitivity training should be an ongoing process and if in health care they are not sensitive who will be and if someone is vulnerable and they are down and they are a visible minority**

**who has a disability plus all the other layers and layers of vulnerability...”**

**“I think government policies should change. I would like to see some faces of colour at point of contact to feel more comfortable. A sense of a community would be great, i.e. referral to community people who understand me. I changed my family doctor because I didn’t feel included in that clinic.”**

- Provide training and information for ethno-cultural/racialized women with disabilities on how they can address the different issues they face at the service and policy levels and fight discrimination proactively

**“I feel and believe its our obligation to some extent to explain things to people introduce myself and don’t define myself as the disability and inform them that this is what is going on for me so that they can be sensitive and at that point if they choose not to be sensitive I know there is steps I have to take after that...”**

- Reinstate the services that have been delisted
- Increase the accessibility and availability of services and the information provided

**“Everyone I have spoken to has immense complaints about health care and it’s not only about color but about the cut backs and prescriptions. We need to have more public awareness about disability and its ironic that people in health care are not educated about disabilities. It’s awkward for me when I go to a pharmacy or a hospital and they don’t know how to deal with me.”**

- Work towards an inclusive society where there is equitable opportunity and access for ethno-cultural/racialized women with disabilities to the social determinants of health with a particular focus on employment, income, housing and lives without violence and abuse.

**“Awareness about invisible disabilities. At my walk-in I feel included because it’s specific to our people. Most of the clinics,**

**here, there populations are all coloured people so their services are pretty good to me.”**

- Increase number of women doctors

**“The people need to be more educated. They need more female doctors because I get agitated to talking with the male doctors.”**

"We Are Visible"

**For more information contact:**

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**Ontario Women’s Health Network**

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Website: [www.owhn.on.ca](http://www.owhn.on.ca)

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## Glossary of Terms

**Access:** Access occurs when members of a group such as people with a disability and/or ethnocultural/racialized women are able to participate actively in any organization but for this study specifically health organizations; as clients, staff members, volunteers, and board members.

**Accessibility:** This results when principles of universal design are applied to facilities to ensure barrier-free access. (See below for the definition of “universal design.”)

**Accommodation:** Supports that persons with disabilities need in order to participate in any activity of daily living, whether at home, in school, at work, the community or for a variety of social, recreational or healthy living needs.

**Anti-racism/anti-oppression/anti-ableism:** An approach that confronts racism, oppression and ableism in all forms. Anti-racism/anti-oppression approaches are based on the idea that racism and oppression result from power structures created by historical, social, cultural, political, ideological and economic forces. Anti-ableism is similar, but it specifically combats the bias that physical or mental “perfection” is a superior state of being.

**Barriers:** An obstacle to accessing a service, 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, lack of understanding of disability, race or women’s issues etc.

**Discrimination:** Discrimination is action or behaviour based on prejudice. Discrimination occurs when an action limits the freedoms and activities of others. It usually takes the form of differential treatment of one individual by another, or the exclusion or restriction of one group by another. Discriminatory behaviour attaches importance to physical differences. It results in differences in behaviour towards people who are perceived part of a group – women, persons with disabilities, people from different ethnic or religious groups, sexual orientation – and has the effect of withholding, excluding, restricting or limiting access to housing, jobs, education, participation, organizations, opportunities and benefits. In order to discriminate, a group must have the social, economic, and/or political power to oppress another group.

**Diversity:** The state of being different or diverse. When used to describe people and population groups, diversity refers to differences or variations in age, gender, race, ethnicity, ability, sexuality and religion, as well as education, professional background, and marital and parental status.

**Equity:** Refers to equality of access. An equity program is designed to remove barriers to equality, by identifying and eliminating discriminatory policies and practices. Such a program should remedy the effects of past discrimination and prevent future inequities.

**Harassment:** Words, conduct or action, usually repeated or persistent, that cause annoyance, alarm, or substantial emotional distress in the person being harassed. Harassment often targets difference – harassment may revolve around race, gender, ethnicity, ability, sexual orientation, religion, age, social status or economic level.

**Health:** Health is a state of complete physical, mental and social well-being, and not just the absence of disease or illness. Well-being is the extent to which an individual or group is able to realize aspirations, to satisfy needs and to change and cope with the environment. Health is therefore a resource for everyday life. Health is a positive concept emphasizing social, physical and personal resources. Health can only be achieved by addressing the social, economic, environmental and political conditions of women's lives.

**Health promotion:** This refers to programs, resources or actions that help people to increase control over, and improve, their health.

**Health services:** Services which ensure the preservation of mental and physical well being as well as the prevention, treatment, and management of illness, offered by the medical, nursing, and allied health professions.

**Universal design:** Universal design is an approach to the design of products, services and environments to make them usable by as many people as possible regardless of age, ability or circumstance.

## Questionnaire

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***Please answer all questions you feel comfortable responding to***

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### **State of Health and Services Used**

(Please indicate your response by circling the best option or marking it with an X.)

1. How do you rate your state of health most of the time?  
(check one only)

excellent  
good  
fair  
poor

2. Do you require extra services or supports in order to have your health needs met? Indicate yes or no.

3. If yes, what services and supports address your health needs?

in home services  
health promotion  
medical services  
disability services  
other (fill in blank): \_\_\_\_\_

4. Do you use alternative health services such as acupuncture, naturopathic, ayurvedic medicine, other? Indicate yes or no.

If yes, please list the services used:

### **Access**

#### *Accessibility of health information and services*

5. Do you access information about health services? Indicate yes or no

If yes, please list the information you access and where you receive this information from:

6. Do you access information about health issues and healthy lifestyles?  
Indicate yes or no.

Please list the information you access about health issues and healthy lifestyles:

7. Is health information available to you in a format that you can use?  
Indicate yes or no.

Please explain:

8. Are you given enough information on contraception and reproductive services to make an informed choice? Indicate yes or no.

Please explain:

9. Do you have access to the health services that you need? Indicate yes or no.

If yes, why? If not, why?

### **Sense of exclusion and inclusion**

10. Do you face barriers when accessing health services?  
Indicate yes or no.

If yes, can you name some of the barriers that you have experienced when accessing health services? Comment on physical, financial, legal, technical and attitudinal barriers:

11. Have you experienced discrimination based on gender, race, faith, language, immigration status, disability, mental health status or other when accessing health services? Indicate yes or no.

If yes, describe the discrimination you faced: how did it impact you both in how you felt, and how you access health services? Please give examples:

12. Have you experienced any form of harassment when accessing health services?  
Indicate yes or no. (If the answer is no, skip to question #14)

If yes, please explain:

13. Did you take steps to address any of the discrimination or harassment you experienced? Indicate yes or no.

Please explain:

14. If you experienced exclusion, what steps have health services taken (if at all) to increase your feeling of inclusion? What else could be done to make you feel included?

15. Please name some of the services that you have accessed that help you to accommodate your health needs.

16. Do any of the health services that you use have an accessibility policy, anti-racism/anti-oppression policy, diversity policy and/or equity policy that you are aware of? Indicate yes or no.

If yes, do these policies have any impact on the care you receive?

### **Over the last ten years**

18. Have you experienced any significant differences in the services that are available in the past 10 years? Indicate yes or no.

19. Have you experienced any significant differences in the quality of the services that are available in the past 10 years? Indicate yes or no.

20. In the last 10 years, have you experienced any significant changes in accessing health services as a ethnocultural/racialized woman with disability? Indicate yes or no.

Please explain:

21. In the last 10 years, have you experience any significant changes (positive or negative) in the quality of health services as an ethnocultural/racialized woman with disability? Indicate yes or no.

Please explain:

22. Any additional comments you would like to make?