

# Table of Contents

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<b>1.0 EXECUTIVE SUMMARY</b>	<b>2</b>
<b>2.0 INTRODUCTION</b>	<b>5</b>
2.1 Goals of the Gateway Project	6
2.2 Project Origins	6
<b>3.0 IMPLEMENTATION OF THE GATEWAYS PROJECT</b>	<b>9</b>
3.1 Committee Structure	9
3.2 Staffing	10
<b>4.0 METHODOLOGY</b>	<b>11</b>
4.1 Participatory Action (User-Driven) Research	11
4.2 Systematic Review of the Literature	13
4.3 Consent and Anonymity	14
<b>5.0 QUALITATIVE NEEDS ASSESSMENT</b>	<b>15</b>
5.1 Focus Group Summary	15
5.2 Participant Outreach and Recruitment	16
5.3 Focus Group Protocol	18
<b>6.0 DATA ANALYSIS</b>	<b>18</b>
6.1 Preliminary Findings	18
6.2 "Bodies" in Relation to Screening	19
6.3 Barriers to Access Created by the Healthcare System	20
6.4 Barriers to Access External to the Healthcare System	21
6.5 Self-Advocacy and Self-Care	23

6.6 Facilitators to Screening	24
<b>7.0 PRELIMINARY RECOMMENDATIONS</b>	<b>25</b>
<b>8.0 CONCLUSION AND NEXT STEPS</b>	<b>27</b>
<b>9.0 APPENDICES</b>	<b>28</b>

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# Gateways to Cancer Screening Project Report

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## Preliminary Findings

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## 1.0 Executive Summary

This report outlines the main activities and accomplishments of the Gateways to Cancer Screening Project. The project is based on the premise that women with physical mobility disabilities have faced significant barriers in accessing cancer screening. The Gateways project developed a series of 5 peer-led focus groups in the Greater Toronto Area where women with physical mobility disabilities came forward to describe their experiences with cancer screening and propose recommendations to facilitate positive change.

Prior to developing the focus group questions we carried out a thorough literature review. A systematic analysis of the existing literature was then conducted and gaps were identified. This review was developed into an article we entitled *Navigating Health Care: Gateways to Cancer Screening* and it was submitted to a peer-reviewed journal called *Disability and Society*, 2008 (in review). A copy of the article can be found in the Appendices of the full report.

The study was conceptualized as a qualitative needs assessment to identify the barriers faced by women with mobility disabilities in accessing screening and existing services as well as identifying specific gaps in services. The Gateways to Cancer Screening project has brought together disability rights activists, community workers, health care providers and academics to assess these barriers, and to stimulate change. The term “Gateways” was specifically chosen to denote facilitators to access care, rather than just identifying barriers. In contrast to traditional social science research that has historically excluded the voices of disabled people (Oliver, 1996), *Gateways* is explicitly designed as a user-driven project. Central to this project is the notion that small focus groups led by research team members who are also wheelchair users will empower the voices of disabled women to tell their own stories in their own language (Bloom, 2002; Thomas, 1999) about their experiences with breast, colorectal and cervical cancer screening.

As researchers we recognized the need to examine the impact diversity has on the experience of screening among women with disabilities and sought to include women who identify as ethno-racial, aboriginal, lesbian/bisexual/transsexual, trans-gendered and/or may be living on fixed incomes. Members of the research team include women with and without mobility disabilities as well as women identifying with other marginalized communities.

There is a difficult and strained history between the medical profession and disabled people that is discussed in detail through this report. This relationship coloured the experiences, attitudes and expectations of women considering and exercising their options in accessing screening. With conscious knowledge of this history, the focus groups were designed by a team of researchers that included both wheelchair-users and health care professionals and the groups themselves were facilitated by wheelchair-users. In this way, we were able to connect both institutional and experiential expertise to develop strong strategies for change in an environment that was clearly welcoming to the voices of participants.

Participants were drawn to the groups as an opportunity to have their voices heard about their experiences and to advocate for change in the provision and delivery of

services. While this was often the primary motive, participants benefited greatly from the educational aspect of the group. The first segment of each session was an information session about types of cancer screening and the health benefits of early detection. In effect, these groups became peer support networks and were ultimately facilitators to cancer screening that people may not have attended otherwise. Peer support workers Nancy Barry and Fran Odette, who are also wheelchair users, facilitated the groups while Nurse Clinician Linda Muraca presented health information and received questions. This process served as a forum to bring women together to talk about health. Small discussion groups facilitated conversations that are entry points into a new way of negotiating healthcare.

Participants opened up to one another about past negative experiences in the healthcare setting. In one particularly potent revelation, two women who attended a focus group together as friends described a shared institutional history where mandatory pap smears were enforced in the institution they lived in. One woman described the physicality and after-effects of the experience this way:

*I had to have [a pap smear] when I was a teenager. It was not a good experience and I swore I'd never go back again. My doctor tries to get me to go and has that disappointed look that I won't do it, but I just can't. He keeps advising me to talk to a nurse practitioner. I say I'll do it one day. Just because it was a bad experience. I'm not comfortable even with putting on a tampon if I have to.*

Women were clear in fore-fronting their histories and bodily experiences within healthcare encounters and outside facing prejudices and normative assumptions about their abilities and identities. Conversations about screening and other healthcare strategies allowed women to connect to one another and allowed us as focus group facilitators to provide answers to questions, and to follow-up after the groups by sending information about healthcare services and specific health questions. We will send short research summaries to all of the participants to ensure that the process respects their input and is not simply an extraction of information.

Just as women described difficult experience, they also provided concrete details about how and why specific encounters worked for them:

*I had an excellent doctor... and we went through a lot of discussion about what would happen and she was even willing to do it at my home. She made sure that everything was done well and some very compassionate nurses came in to help out as well. They can make accommodations. Sometimes, it's about trying to have the assertiveness to say what would help you – "How can you arrange for this? Where can you get it?"*

Women were active participants in their own healthcare, describing both facilitators in clinical settings and their own work and self-advocacy strategies. In addition, participants provided rich recommendations for how they saw cancer screening processes improving to accommodate their needs.

Major recommendations within our preliminary findings:

- More places with accessible exam tables and screening technology and on-site attendant care that are clearly publicized to the disability community.

- Strategic health messaging with disability-positive images and specific information for women with disabilities to support self-advocacy in accessing screening
- More personnel to address disability-related needs and anxieties prior to screening procedures
- On-site health education sessions for women with disabilities on screening guidelines, procedures and body-specific strategies for optimal care
- Disability Training for Health Care Professionals and clinical staff at all levels on appropriate and clear communication, compassionate behaviour and best practices
- Creating safe and positive spaces for women with disabilities from LGBTQ communities, marginalized ethno-cultural communities, low socio-economic status and various ages
- Patient-centred and integrated preventive cancer care that includes more options and less coordinating work for patients

#### Knowledge Transfer – Our Next Project

The research team's objective, reinforced by the participants' clarity about the changes that would benefit women with disabilities, is to secure resources and opportunities both to pilot the learnings in one or more settings. We would like to develop a creative resource that would allow health care settings across the Province to learn from and implement these important improvements to access, screening and early detection.

The recommendations proposed by focus group members participating in the research process are a form of specialized experiential knowledge that needs to be shared with healthcare providers and implemented. As a research group we would like the "knowledge transfer" phase of this project to be as participatory and user-driven as the data collection and analysis. In order to maximize the investment of time and finances in the earlier phases of the project, the research team is proposing a process of creative knowledge transfer for the next phase. We see the potential of involving research participants who are wheelchair users in the creative process of educating healthcare professionals about their needs in accessing cancer screening.

The continuation of an inclusive, participatory action approach to knowledge transfer is necessary to ensure that these recommendations are implemented and have the impact and audience they deserve.

## 2.0 Introduction

In Canada, universal health care is a social and political right and a founding principle of the Canadian health care system. Health care access can be included as a basic tenet of human rights, social inclusion and a guarantee for full participation. Yet despite these ideological principles, many people in Canada continue to experience marginal status in their access to health care based on disability, race, sex, gender, sexual orientation, income, geographic location and/or resulting from experiences of trauma, violence, immigration or colonization (Raphael & Pederson, 2006). In Canada there are over four million people with some kind of disability (Statistics Canada, 2007). Preventive health services are offered routinely to individuals by health care professionals and are designed to prevent illness or detect it at the earliest possible time so it can be treated. Despite the fact that women with disabilities have the same biological risk as non-disabled women for developing all cancers, women with mobility impairments face system, architectural, procedural and attitudinal barriers to preventive cancer screening (Nosek, Young, Rintala, Howland, Foley & Bennett, 1995; Welner 1998). As a result, women with disabilities are frequently excluded from care that most Canadians experience as a basic right.

The Gateways to Cancer Screening Project was formed to conduct a “qualitative needs assessment” to identify the barriers faced by women with disabilities to access screening, existing services and identify specific gaps in service. The following participant remarks sum up some of these gaps:

*What scares me is hearing people say that they had to be the ones to initiate the cancer screening. I sort of look to my doctor to tell me what has to be done and when. I don't particularly like going for tests unless she tells me. But if she doesn't tell me, I guess I have to be more on top of what I'm doing and make sure it should happen.*

*Even the doctors you go to, I've asked questions as to when I should start doing specific tests. They said, “We don't know where to send you – I have to do some research.” When the medical profession can't point you in the right direction... And these are the people you look at but they don't have the resources or knowledge. They have the ability to gain the information but they don't have the knowledge around the disability issues. And who else provides that service if they don't?*

People with disabilities are four times as likely as able-bodied people to report an inability to obtain required medical care when it is needed (Canadian Council on Social Development. CCSD's disability information sheet: No. 9, 2003. The health and well-being of persons with disabilities, [www.ccsd.ca/drip/research/dis9/index.htm](http://www.ccsd.ca/drip/research/dis9/index.htm) 2006 Jul 10). People with disabilities, in particular, women with mobility disabilities, clearly need improved access to quality health care, specifically when it comes to cancer screening. In addition to interventions at the systemic level, healthcare professionals can also individually improve the care that they provide. It is our hope that through this research initiative, healthcare providers will become more enlightened as to what they can do to make a difference to the health of this very important and growing group of patients.

## 2.1 Goals of the Gateways Model

- to assess the needs of diverse women with physical mobility disabilities in accessing breast, cervical and colorectal screening services and determine the gaps and barriers associated with accessing these services
- to develop a series of recommendations to be shared with the key stakeholders involved in the delivery of screening services
- to focus on implementing these recommendations
- to produce new areas of knowledge that can be effectively transferred to key cancer control professionals that benefit people with disabilities

## 2.2 Project Origins

Through various workshops relating to “Health Issues for Women with Disabilities” hosted by the Centre for Independent Living in Toronto (CILT), it was recognized that the need to increase the level of awareness of screening for breast, cervical and colorectal screening among disabled women in the Toronto area. The recent cancer statistics are a real cause for concern—every eight minutes, two Canadians are diagnosed with cancer and one dies from it. As we all know, cancer takes the lives of more people in Canada than strokes, respiratory disease, pneumonia, diabetes, liver diseases and HIV/AIDS combined.

Prevention and early detection and screening are seen as ideal areas of intervention in the cancer control continuum. For example, a high quality organized cervical screening program with high rates of participation can reduce new cases of cervical cancer, and deaths from it by 80-90% compared with no screening; breast screening can find cancers when they are still small and can respond better to treatment and screening for colorectal cancer is an effective way of reducing colorectal cancer. Ontario’s rate of new colorectal cancer cases is among the highest in the world.

For women with disabilities access to screening and support has been a challenge.

- Women with disabilities have the same biological risks as other women for developing all cancers. Unfortunately, barriers to effective cancer screening for disabled women include lack of knowledge among these women, neglect on the part of health-care providers, and physical access barriers (Welner, 1998). Together, these factors may delay diagnosis and treatment of many common malignancies. Women with disabilities, in particular those who are older, are less likely to receive regular



Pap tests and mammograms (Nosek & Howland, 1997).<sup>1</sup>

- Although some of the barriers to cancer screening are structural, such as inaccessible examination tables, stirrups, and lack of appropriate examining instruments for impaired women, studies show that physicians sometimes fail to recommend any screening for women with disabilities (Nosek, Young, & Rintala, 1995).<sup>2</sup>
- Some disabled women describe health-care providers as insensitive to and unaware of disability issues and the way they affect reproductive health (Nosek, Young, & Rintala, 1995).<sup>3</sup>

In our experience, women with disabilities continue to face barriers in accessing health services in a multitude of ways. These barriers are exacerbated when the needs for basic health care increase with age, and when gender or language issues enter the mix. There is a definite need for more appropriate and accessible screening measures, disability sensitivity, and for support groups for women with disabilities who do have cancer.

As a result, the Centre for Independent Living recognized the need to increase the level of awareness of screening for breast, cervical and colorectal screening among disabled women in the Toronto area. Partnerships were then developed with the Canadian Cancer Society, the Marvella Koffler Breast Centre and the Faculty of Nursing, University of Toronto to conduct a qualitative needs assessment to identify the barriers faced by women with disabilities to access screening, existing services and identify specific gaps in service. A working group was then set up to act on and monitor the implementation of the recommendations, consisting of the partners of the project, as well other key contributors including the Anne Johnston Health Station, Springtide Resources (formerly, Education Wife Assault) and the Ismaili Cancer Support Service.

The Centre for Independent Living in Toronto (CILT) Inc. is a non-profit resource organization, consumer-controlled and community based. CILT is funded through the United Way, City of Toronto grants, Federal and Provincial government grants, donations, earned income and membership support. In a consumer-controlled, community-based resource framework, known as the Independent Living Model, the Centre helps people with disabilities learn Independent Living skills and integrate into the community. CILT is one of 25 members of the Canadian Association of Independent Living Centres (CAILC) and one of 10 members of the Ontario Network of Independent Living Centres (ONILC). Funded primarily by the United Way of Greater Toronto, they also receive funding, in part, through the City of Toronto and

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<sup>1</sup> Steinstra, Deborah and Gucciardi Enza. "Disabilities." *Ontario Women's Health Status Report*. Ontario: Ontario Women's Health Council, 2002. 146 - 161

<sup>2</sup> Steinstra, Deborah and Gucciardi Enza. "Disabilities." *Ontario Women's Health Status Report*. Ontario: Ontario Women's Health Council, 2002. 146 - 161

<sup>3</sup> Steinstra, Deborah and Gucciardi Enza. "Disabilities." *Ontario Women's Health Status Report*. Ontario: Ontario Women's Health Council, 2002. 146 - 161.

the Ministry of Health.

CILT operates on the philosophy of the Independent Living movement which was developed in response to traditional rehabilitation services models. CILT's aim is to develop and implement dignified social services that empower individuals rather than create dependencies. We encourage people with disabilities to take control of their own lives by exercising their right to examine options, make choices, take risks and even make mistakes.

The Diversity and Cancer Control Teams of the Canadian Cancer Society has provided direct and in-kind support for the project, while ensuring that the project also reflected the diversity that exists in Toronto and that the recommendations from the research will be carried out in a meaningful and sustainable way. Previous research has been conducted examining the barriers that women with disabilities face in accessing preventative cancer screening; however, most of the research has been conducted outside of Canada. No existing research has explicitly examined the experiences of women with disabilities from a Toronto perspective. One of the aspects that make Toronto unique is our demographic diversity.

A central aspect of this project was examining the intersectionality of identities and exploring how intersecting identities impact a woman's experience with screening processes. Intersectionality is defined as the intersection of ethnicity, race, class, gender, age, ability, sexual/affectional orientation, physical size, etc. in the 'lived experience' of individuals, which is influenced by the simultaneity in time and/or place of these factors. In other words, it is "people's exposure to the multiple, simultaneous and interactive effects of different types of social organization or oppression in which they are located" – a person's social location (T. Rennie Warburton, October 7, 2002, in Anderson et al, 2003, p. 203). Many women face barriers to the health care services in their communities. Cultural differences, time, costs, childcare, knowledge deficits, language and literacy all play a role in how easy or difficult it may be for women to receive optimal healthcare (Thurston, 1996).

## **3.0 Implementation of the Gateways Model**

### **3.1 Committee Structure**

The committee was designed in an egalitarian fashion with all members of the research group holding the status of co-investigators and participating in consensus decision-making. The Research Working group consists of:

- Nancy Barry (Centre for Independent Living in Toronto)
- Fran Odette (Springtide Resources)
- Samira Chandani (Ismaili Cancer Support Network)
- Julie Devaney (Research and Community Outreach Coordinator, Gateways)
- Sharmini Fernando (Canadian Cancer Society)
- Linda Muraca (Marvelle Koffler Breast Centre/ Mount Sinai Hospital)
- Jan Angus (University of Toronto, Faculty of Nursing)

The Advisory Group consists the members of the Research Group and:

- Lucy Costa-Nyman (Anne Johnston Health Station)
- Lynne Penberthy (St. Michael's Hospital, Ontario Breast Screening Program)
- Lisa Seto (PhD student, Faculty of Nursing, University of Toronto)
- Kimberley McKennitt (Centre of Independent Living in Toronto)
- Tara Geraghty (Former Coordinator, Gateways)

The Research Working group met bi-monthly through the process of coordinating the focus groups and analyzing the data. The Advisory Group meets at the beginning and end of each research phase to provide feedback and direction

### **3.2 Staffing**

The Community Outreach and Research Coordinator worked for 16 hrs a week under the supervision of the Project Manager at the Canadian Cancer Society until the end of February 2008. . The project coordinator collaborated with CILT and other organizations to facilitate awareness of the project. The responsibilities of the project coordinator included:

- Community Outreach with diverse organizations and populations
- Writing, editing and submitting ethics applications
- Liaising with focus group participants in advance of, during and after focus groups
- Coordinating physical space and transportation requirements for focus groups
- Coordinating research group meetings
- Researching and co-writing manuscript for publication
- Performing administrative tasks for data analysis meetings
- Engaging in data analysis of transcripts
- Inputting codes in Nvivo software to organize themes in the transcripts
- Preparing preliminary report of findings

In addition, a research assistant working at the University of Toronto through Dr. Jan Angus was able to allocate hours towards the systematic review of existing literature and the production of the manuscript which is currently in review

## 4.0 Methodology

### 4.1 Participatory Action (User-Driven) Research

When the original Gateways proposal was written in August 2006 we thought qualitative description would be the best methodological approach to obtain the information we sought. We wanted to *describe* the views of women with disabilities and illuminate the institutional constraints and facilitators to breast, cervical and colorectal screening. However, when our newly formed Advisory Group consisting of members from the disabled community met during one of the initial meetings it was clear that this approach did not incorporate the most important aspect of the Social Model of disability - **inclusion**.

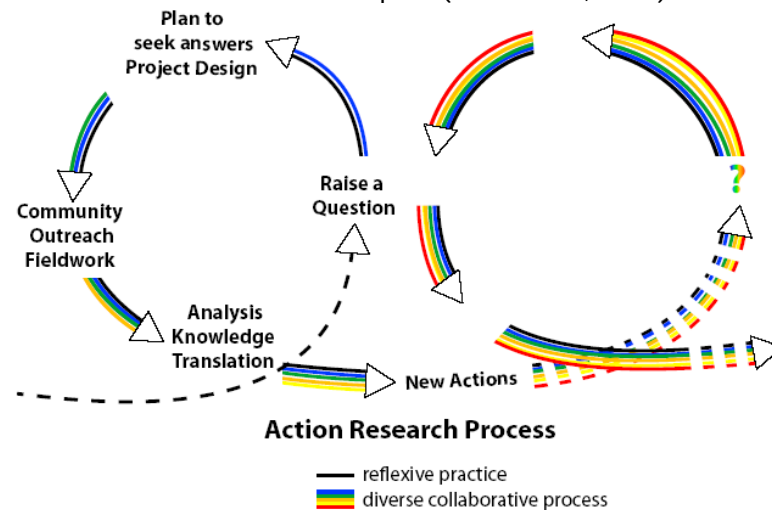
Historically, "experts" have researched various aspects of the disabled community with little or no input from members of that community. Researchers from governments, medical agencies and universities posed the research questions of interest, studied persons with disabilities, *extracted* data and wrote papers or reports with no contribution from disabled people. Disabled people were the research subjects with no voice or control as to what the questions should be, how and who would carry it out, or how the results would be directed to the problems identified in their communities.

Our Advisory Group was very committed to a participatory consensus-based approach when developing the research framework. The Centre for Independent Living, one of the founding partners for this project, adheres to principles such as *consumer control* and *full participation*. It was therefore crucial that members from this group who were consultants, nurses and academics listen to the entire group and change our approach. All members would fully participate in this project's development having equal input at all stages of the research and knowledge translation. Agreeing to adopt this fundamental change we later reflected upon was the foundation of trust necessary to move ahead with Gateways as a cohesive project team. We also acknowledged that the project would take longer to complete because of consensus-based decision making process however, we believed this approach would lead to richer and more meaningful results.

As a group we moved from the descriptive method of inquiry to participatory action research (PAR) methodology. In PAR, "the emphasis is on relinquishing control, learning through mutual interactions between researchers and participants, and giving voice to those who would not otherwise be heard" (Specziale & Carpenter, 2006, p. 329). This methodology included participation and most importantly an action component. The group believed that the action had to be the knowledge translation that would be carried out with cancer screening organizations and the focus group participants. This would be the initial step of raising awareness amongst these service providers that could possibly lead to informed changes in practice. Focus group participants would also be empowered by the collectivization of their voices.

PAR is a cyclical process involving reflexivity, diverse collaboration, raising crucial questions, planning to seek answers, choosing a project design, community outreach and fieldwork and finally data analysis and knowledge translation. With new

actions other questions will be raised and the cycle continues again. This process is depicted in the model below that we adapted (Wadsworth, 1998).



Once we had chosen our research method we decided that focus groups would most likely be the best way to collect the data with peer facilitators asking the questions from our team. Focus groups allow participants to build on each others ideas that may not have been obtained in a one to one interview. They are also ideal when dealing with sensitive topics as it gives the participants the control in terms of what they will say and when to share it.

We then needed to write a consent form, letters of invitation to organizations who provided support to women with mobility disabilities, create recruitment flyers and develop a research protocol with all the activities and questions we intended to carry out and pose during the focus groups.

When we developed these documents our group agreed that it was necessary to obtain an ethical review from an accredited Research Ethics Board (REB). Ethics approval would also be required when we were ready to publish our findings in the future. REB approval would ensure that our research met the highest ethical and scientific standards and would protect our focus group participants. One of the nurses on the Gateways project team suggested we submit an Ethics application to her hospital due to ease of access.

Initially the hospital REB's questions and concerns were easily answered but, with each revision their comments became more challenging to answer which led us to believe that they were critiquing our project using a quantitative research lens. They criticized terminology that was written by women with disabilities and did not know how we would deal with people with multiple social identities (i.e. ethnic, transpeople etc.). This never ending questioning process delayed our project by four months and in the end they would not give full ethics approval. They suggested that we would benefit from an outside review of our project. We did have our project reviewed by Dr. Elizabeth Peter who is a Faculty of Nursing Associate professor and is also a Member of the Joint Centre for Bioethics. She reviewed all of our materials and found nothing that was of concern in terms of research methodology or ethical conduct.

We decided at this point in June 2007 to apply to the University of Toronto REB because we thought they would have a greater understanding and expertise with qualitative research projects. Their initial comments were, “this appears to be a very important study and the protocol was very thoughtfully prepared”. After their review it was necessary to make a few minor changes and we received full ethics approval on July 21, 2007.

## 4.2 Systematic Review of the Literature

In the early stages of the Gateways project, a review of existing studies on cancer screening for disabled women was undertaken. A systematic review of the literature was conducted to find existing studies on preventive cancer screening in women with physical disabilities. An on-line search was conducted to review information accessible through websites, and to access electronic grey literature produced by, for example, government agencies, professional organizations, non-profit organizations and research centres. Electronic grey literature was sought because information on the internet has become a major source for dissemination for many organizations. Electronic resources may easily be accessible by women with disabilities as well. For some women with disabilities, on-line access to cancer screening information may be the preferred way of accessing medical information (Crooks, 2006). A search was also conducted of published literature using Medline, CINAHL and Scholars Portal. The studies we found produced some useful statistics about rates of cancer screening that were highly relevant to our research project. Missing in all of the previous studies and literature we reviewed, was analysis of intersecting oppression between disability and other marginalized identities, any theoretical interrogation of bodily issues in the screening process.

Out of this document we began the process of theoretically situating this material, and in doing so created a theoretical grounding for our data analysis. We developed a framework to examine the material and produced a scholarly article that is currently in review at the journal *Disability and Society* in the UK. In the article we draw upon existing literature to examine current screening patterns for women with disabilities. Our goals are to identify barriers and facilitators to screening and identify the gaps in the existing literature related to issues of diversity. We focus on cervical, breast, and colorectal screening of women with physical mobility disabilities. We also draw on international sources and studies to contextualize and theoretically ground these barriers at a macro scale. We employ the structural critiques offered by the Social Model of Disability to expose gaps in public health data collection that obscures social and political variants in access to health care. Our starting point in this analysis is that health care experiences are ultimately *embodied* experiences. To address the issues surrounding these clinical encounters we begin at a micro-level by exploring the interactions between disabled women and their health care providers through the lens of feminist frameworks about our bodies (Shildrick & Price, 1999). We take the position that women's stories about their experiences can elucidate the intersectional nature of identity (Bloom, 2002; Thomas, 1999) and the implications of different types of oppression at a macro scale. In doing so, we recognize the emancipatory potential of flesh and bones stories in qualitative analysis to facilitate social change. (Appended)

### 4.3 Consent and Anonymity

During the focus groups a facilitator read the entire consent form aloud and gave time for questions (Appended). Due to the interconnected nature of the disability community in Toronto we made it clear that it was not possible to guarantee participants' complete anonymity or confidentiality. However, the working group took the following measures to enhance the safety of participants and the input they chose to share.

- All working group members signed a contract of confidentiality
- To protect the safety and confidentiality of focus group participants as well as facilitate data analysis and synthesis, participants were asked to name themselves to the group, but they were not identified in the transcript or in quotes used in the dissemination process.
- The signed consent forms were collected and kept separate from the transcriptions to further protect the identity of participants.
- Data in the form of audio-recordings were only heard by the research sub-committee for the purpose of transcription.
- The transcribed data was, and still is, in a locked cabinet at the Centre for Independent Living in Toronto and will only be viewed by members of the working group for the purpose of analysis.
- Direct quotes were included in the final report to enhance the credibility of the findings and reflect participants' first-voice experiences and input.
- Only the final report will be available to other key stakeholders.
- Participants will have the opportunity to see the final report prior to widespread dissemination in order to validate the accuracy and representativeness of the analysis.
- Any resulting forum or meeting in the knowledge transfer stage would have included focus group participants as invited guests.



## 5.0 Qualitative Needs Assessment

At this time we have completed the data generation/focus group phase of the project. Each group consisted of an educational segment where a nurse clinician presented and answered questions about cancer screening, followed by a long facilitated discussion about participants' experiences accessing screening. We have received extremely positive feedback from participants about both the educational and discussion elements.

Prior to the development of our focus group protocol we conducted a group session with "key informants" in Toronto. We met with disabled women who are also established community activists and/or experts in the field of disability health. After an extremely rich theoretical discussion we formed our focus group protocol. Most notable in our key informant group, was the experience of disabled women entering clinical encounters where professionals did not address preventive health care at all, instead focusing in on the disability as the "presenting issue", irrespective of whether or not the woman herself was seeking medical advice regarding her disability. In addition, after describing a lifetime of challenges with medical professionals based on attitudes and approaches to disability, women were very unlikely to seek any kind of medical support unless it was absolutely necessary.

This perspective from our key informants identifies a major gap in the existing literature on preventive care. Because none of the studies we found actually allow women the opportunity to tell their stories, they miss the fact that previous experiences that are apparently unrelated to cancer screening on the surface, have a profound impact on whether or not disabled women will advocate for and/or choose to engage in preventive health care services. In addition, by designing this project as user-driven, we very consciously allowed the stories and health care experiences of our facilitators to engage with the stories of our participants.

### 5.1 Focus Group Summary

Women were able to discuss their experiences with cancer screening and share insights, **barriers** and **facilitators** of screening in a "safe" and peer-supportive environment. Key players involved in each focus group were as followed: three peer- facilitators, one peer support provider, two note takers (both bound by confidentiality), the attendant service provider and the focus group participants. It is important to note that the attendant service provider remained outside the room where the focus group was taking place to ensure confidentiality. However, the participants were assured that should they require the attendant at any time, she would be called back into the room. In total, five focus groups were held with individuals who self-identified as women living with a mobility disability: two at the Centre for Independent Living in Toronto, two at the Canadian Cancer Society and a final one in Peel Region. Each group was led by peer facilitators.

A total of 24 women have participated in the groups.

The breakdown is as follows:

Date	Location	Number of Participants
Wednesday August 14 <sup>th</sup> 2007 @ 5:30 pm	Canadian Cancer Society	3
Saturday August 18 <sup>th</sup> 2007 @ 12 pm	Centre for Independent Living in Toronto	5
Thursday September 13 <sup>th</sup> 2007 @ 5:30 pm	Canadian Cancer Society	4
Saturday September 15 <sup>th</sup> 2007 @ 12 pm	Centre for Independent Living in Toronto	5
Saturday September 29 <sup>th</sup> 2007 @ 12 pm	The Coalition for Persons with Disabilities in Mississauga	7

## 5.2 Participant Outreach and Recruitment

The participatory research model had as its foundation the ability to build trust within the community, thus a community development approach was utilized to begin the outreach process. The qualitative needs assessment took place in the form of focus groups, where researchers/facilitators interviewed representatives from the disabled women's community including ethno-racial women, lesbian and bi-sexual women, aboriginal women as well as women living on fixed income. From the results of the needs assessment, the project team developed a series of recommendations to be shared with the key stakeholders and cancer control professionals involved in the delivery of screening services and to focus on implementing these recommendations.

We deliberately attempted to hear from women from diverse communities, including the lesbian, bisexual, trans-gendered, trans-sexual, ethno-racial and aboriginal communities, in order to truly reflect the diversity that exists in Toronto and make the resulting recommendations relevant to as many people in Toronto as possible. Prior research on women with disabilities has implicitly assumed that either all women with disabilities are the same, or that disability is the singular central aspect of these women's lives. Women with disabilities come from diverse socio-cultural demographics, and these aspects of life impact the experience of disability and one's relationship with the healthcare system.

In order to achieve this goal, the research team outreached to the various communities highlighted above through various mediums, including sending recruitment flyers to a wide variety of disability organizations, as well as those serving women from the lesbian, bisexual, trans-gendered, trans-sexual, ethno-racial and aboriginal communities. Through partner organizations including the Centre for

Independent Living Toronto, the Anne Johnston Health Station, Springtide Resources and the Ismaili Cancer Group, among others, a wide recruitment was conducted through newsletter articles, website postings, individual telephone calls, circulation of outreach flyers and word-of-mouth. All women interested in participating as a focus group participant were asked to contact the Project Coordinator for more information.

#### Demographics:

Demographic	Number of Participants	%
Young women (under the age of 30 years)	2	8
Lesbian, bisexual, transsexual, transgendered or queer	3	12.5
Women from ethno-cultural groups	7	29
Women living in poverty or economic hardship	7	29

A list of agencies to contact for recruitment (Appended) was developed by the Community Outreach Sub-Committee (comprised of random members of the project team), in order to help the project coordinator reach and build relationships with marginalized groups and recruit focus group participants. Extensive outreach occurred to ensure that the project had the widest possible buy-in. Recruitment for participants was conducted through mass mailings of recruitment flyers for potential participants (Appended), and other organizations who could possibly distribute flyers to their client base (Appended), through CILT's website and various newsletters and publications distributed through the agencies represented on the project team, and word-of-mouth.

Once the women expressed interest in participating, they were provided with more information about the project, and asked a series of questions in the form of a Participant Questionnaire (Appended), which was used as a screening tool to determine which focus group they would best fit into. The women had to be at least 18 years of age, live in the General Toronto Area, and have had no previous history of breast, cervical or colorectal cancers. Additionally, they were asked if they required any accommodations (i.e. attendant services, childcare compensation) in order to make it easier for them to attend the focus group. Each participant was also compensated for their travel expenses (i.e. TTC tickets).

The recruitment process was designed to better understand the participants and to ensure that the focus groups were not only a place where we asked questions and received input, but also a place of learning where the participants received an in-depth awareness session on cancer screening provided by a nurse clinician.

### 5.3 Focus Group Protocol

The **facilitators** had three primary responsibilities in conducting focus groups:

1. ensure that major topics are sufficiently addressed by participants
2. encourage that all participants are able to contribute to the discussion, and create opportunities/space to those participants who are less vocal
3. promote group rapport and interaction within a short time span

In short, the facilitators balance conduct of the interview process while moderating group dynamics during the focus group session.

At the beginning of each focus group, participants were given a written document, providing them with information on the background of the study, the purpose and design of the study, the length of the study, possible side effects and risks, possible benefits, compensation (each focus group participant received a \$50 honorarium for their participation in the study), description of the research team, the fact that their participation in the study was completely voluntary, and that they could refuse to answer any question at any time, and a confidentiality form which they were asked to read, ask questions about and sign (Appended).

To ensure the emotional well-being of focus group participants, we ensured that a social worker or supportive staff person was available at each of the sessions if debriefing was required. The key logistic issues were around wheelchair accessibility and transportation. Scheduling had to be exact to ensure that women could make their Wheel Trans pick-ups on time. Focus groups often started late because we were dependent on the reliability of Wheel Trans which rarely arrived on time.

## 6.0 Data Analysis

The discussions were transcribed at the time by professional transcriptionists. Once all of the focus groups were complete we began meeting every two weeks to review the initial transcripts, developing “codes” to analyze the themes being raised by participants. Once we established a code list, we broke into smaller groups to analyze the transcripts in greater detail. During this process the project coordinator began inputting codes into the data analysis software NVivo.

### 6.1 Preliminary Findings

Past research, both Canadian and American, has stated that overall, there seems to be five categories of barriers for this population: (1) Physical Barriers; (2) Communication Barriers; (3) Attitudinal Barriers; (4) Economic Barriers; and (5) other related barriers.

Physical barriers commonly experienced by women with mobility disabilities have been that mammogram machines and scales that require a patient to stand, or exam tables that can't be lowered for wheelchair transfers. Women may find it painful or physically impossible to position appropriately on basic medical equipment.

Communication barriers can also present for women with mobility disabilities who also have limited communication with hearing or visual impairments. Essential health information may not be available in a form they can access, including Braille, large print, audio recording or simplified language.

Attitudinal barriers have played a large role in how the general population views people with disabilities. Misguided information, or 'myths', have played a large impact on how people with disabilities are often seen and treated by others. Disability training for providers and medical students is needed to reassess negative attitudes and faulty assumptions. Medical professionals often assume that women with significant disabilities are asexual and may fail to provide essential preventative care such as breast exams, mammograms and pap smears.

Economic barriers may also play a significant role in preventing women with disabilities from accessing health care. Additionally, medical exams and routine procedures may take significantly more time for people with disabilities, but reimbursement does not compensate for the additional time, providing a financial disincentive to health care providers.

Discussion during the focus groups indicated that many women attended out of an ongoing interest in personal health. They were keen to learn more about cancer prevention, and they also shared detailed information about their established routines of self care. This dialogue indicated that the participants were highly conscious of health related matters and were regularly engaged in activities to promote and maintain their health. Many were very knowledgeable about nutrition, medication side effects, and alternative therapies. They spoke of numerous health care access barriers and constraints and it became apparent that many were anxious to avoid episodes of ill health because of past negative experiences and the additional effort involved in seeking care and treatment. Although a small number received cancer screening services at some point in their lives, many had not. When information about cancer screening was presented at the beginning of the sessions, the frequent questions indicated that many women were not receiving sufficient information from their primary care providers. Furthermore, some who did know about cancer screening were not receiving these services.

In the following sections we will outline some of our major themes and provide a few exemplary quotes to demonstrate the theoretical richness of the focus group discussions.

## **6.2 "Bodies" in Relation to Screening**

One theme we noted across all the focus groups was how participants fore-fronted their bodily experiences. Our approach to examining these "body" themes stands in contrast to existing literature and studies which has not looked at the individual bodily issues of disabled women accessing cancer screening.

After reviewing some of the node reports from the data we organized in NVivo, we selected the following quotes to highlight the embarrassments, vulnerabilities and bodily predicaments experienced during screening:

*I know that at my doctor's they do have a bed that they can lower. But I transfer myself. If I couldn't, it would be difficult to be accommodated. I can see that if I couldn't do it myself, they wouldn't be able to do it for me. It would mean having to ask someone else to go with me. And who wants to have someone else in the room when you're having a Pap test done?*

*I always bring someone with me to do the lifting and holding of my legs. It's been awfully painful. I figure, though, it's better to do it and get it over with.*

*The reaction I get [at the hospital] is kind of surprising given that they are healthcare professionals. I come in with a motorized chair and they still ask me if I can jump up on the table. I will of course need some assistance. Then they are so awkward, attempting to get you where you need to be, to be examined, and they don't follow my directions in terms of how to lift. If I could lift myself, I would do it... But I expect help at the hospitals, it doesn't have to be about cancer, it can be about anything.*

Although it is well known that women with mobility disabilities frequently encounter architectural barriers to access, the focus group discussions illuminated many additional constraints. These ranged from subtle to obvious barriers, and often worked in combination to create complex, frustrating situations for women who sought cancer screening or other forms of health care.

### **6.3 Barriers to Access Created by the Health Care System (HCS)**

Anecdotes highlighted that health care is structured according to normative assumptions about consumers. These assumptions govern all institutional arrangements, including a) referral, intake and appointment scheduling policies and procedures, b) type and placement of furniture within waiting rooms, c) expectations, attitudes and knowledge of health professionals, and d) design and use of specialized equipment for screening.

Many women in wheelchairs cannot transfer themselves or be transferred onto standard examining tables. Similarly, women using wheelchairs may be unlikely to find accessible mammography machines to accommodate them in their chairs. And women (including seniors) who have tremors, who experience spasms, or who lack the stamina to stand at an imaging machine also should be seated for accurate screening. Many healthcare providers who focus on the area affected by the disability might not encourage women to regularly examine their breasts. Also, women with disabilities are often not identified as an underserved population for breast-cancer screening. Thus, they are not specifically targeted in education and outreach efforts by breast cancer organizations (BHAWD, Breast Health Access for WWD. Berkley, California).

*When I got to [the hospital] they took me to the dressing room. They gave me a gown, and I told them I couldn't use this change room. They said, "There is no accessible change room". They told me I can use the examining room. I sat in the scary chair and I found that when I said I didn't want to do the scary chair any more and stated that I'm staying in my chair, my chair was high enough... but I still had to scoot forward for the sideways one.*

*When I was younger I was told that I wouldn't live past 30 so I decided not to take care of some things. However, when I passed 30, I began to wonder if it's true what they say.*

*I have no family and I have no one to be my advocate. Right now I'm my own advocate. If I want a test now, I have to literally go and beg. The politics I've had to play to get tests are ridiculous. When you're disabled, I find you're put on the lowest part of the list – you're not that important because you don't contribute to society.*

Patients with mobility disabilities often have complex medical conditions requiring that multiple issues be addressed when they visit a physician. They may also require additional time and assistance to move about and communicate. Some provinces have a fee code for chronic-care services that partially compensates physicians for the extra time required. However, until adequate numbers of physicians are available and fee-for-service physicians feel adequately compensated, patients with disabilities are likely to continue to have difficulty obtaining comprehensive care.

*...The medical system is set up so that time is a real factor. I feel like the doctors don't have time to sit down and actually have a conversation with me... It's time – they don't have time to do research, and they don't have training to do some of these things. They should investigate how to talk to people and how to deal with people.*

#### **6.4 Barriers to Access External to the Health Care System**

The HCS was not the only source of barriers to cancer screening identified by the women. In order to connect with health services, other resources were required but could be frustratingly difficult to obtain or coordinate. These services were separate from the HCS; hence they presented additional layers of administrative complexity.

Transportation was a major problem cited by most of the participants. Wheeltrans and health services have several properties in common: they are both structured around the requirements of service providers, subject to unpredictable delays, and intolerant of lateness or last minute rescheduling. Women were late for appointments because of Wheeltrans delays or missed pick up by Wheeltrans because of long waits in clinics. Inclement weather intensified these challenges to intolerable levels.

Attendant services were often required for women to attend health appointments and manage self care. These arrangements also had to be carefully coordinated and scheduled. Access to attendant services and assistance with screening activities such as breast self examination or stool testing was limited by payment structures, job descriptions and scheduling restrictions. Specifically, colonoscopy screening preparation and stool testing designed to screen for colorectal cancer at home produces significant challenges for women using wheelchairs and requiring attendant support for using the toilet:

*The methods they recommend should be sterile – and the methods are more able-bodied ways. If you don't have family members or attendants, it won't work at home. I see this as a big obstacle.*

*"I've had a colonoscopy 3 times. They gave me a bottle (which weighs more than I do!) and I know there are other delivery systems that don't require this endless drinking. I took my father in a few months ago and he was given 3 little containers to drink and it worked on him. My suggestion is that because it's difficult to get off from a wheelchair, that the doctors be more informed on elimination processes available."*

*...one of the problems of being disabled is: yesterday morning I woke up with a bladder infection. I called, they asked what I normally take, and I took something I'd never taken before. A neighbour of mine was coming down – she is in a wheelchair. She said she doesn't take any prescriptions because they cause diarrhea. She refuses but she takes cranberry capsules and she says she takes one to two every day. So I will look into that. She said she is too scared to take the chance when she sees the risk.*

*I live in a building that provides support, but it's very difficult to get a staff person available [to come to medical appointments]. So I don't ask for that type of assistance unless I absolutely need it. I've gone to all of my doctor's appointments by myself also due to the privacy issue.*

*For a lot of the healthcare stuff where you have to get out of your wheelchair, it's hard to get an attendant to help me.*

Women who repeatedly confronted these issues hesitated to make subsequent contacts with some services. Past negative experiences with health care, when combined with social exclusions and ill treatment encountered in other settings, led to a cautious and strategic approach.



*Sometimes your concerns aren't taken seriously... Last week I was with someone not in a wheelchair, and I went to pay, and the cashier was looking at my friend, talking to her and handing her the change after I just paid her. I've had that a few times. The few times I've actually opened my mouth to say that I'm the one making the purchase and then the change comes to me.*

Some participants told us that they learned to avoid certain providers or clinics, but had to do additional work to seek better arrangements.

In summary, multiple constraints interacted to impede access to cancer screening. These included characteristics of the HCS, transportation services, and attendant services. Participants indicated that they were also wary of expected social discomfort and harboured misconceptions about screening. However, they were actively involved in circumventing many of these obstacles as described in the next section.

## **6.5 Self Advocacy and Self Care**

Despite – and perhaps because of – these multiple challenges, the women were proactive in protecting their health needs. While many were not engaged in regular cancer screening, they were knowledgeable about their own health issues and highly attuned to the shifts in their bodily wellbeing. They provided examples of strategies to avoid stress and protect themselves from illness. Strategies were learned through trial and error, active engagement with a wide variety of information sources, contact with peers, and, occasionally, tailored teaching by health professionals.

*I feel more than my doctors feel, that there are certain things to watch for. It's me who tells them to watch my liver, my urine, and so on. I don't think I've ever had a doctor that's offered to give me a physical. I'm almost always the one who initiates that process.*

*I go to a lot of doctors and I do my own research and I'm finding that I really know more than the doctors. I find that my illness is unique, just as many types of cancer are unique.*

*For me it's knowing your own body – that's very important. And being aware of what's "normal" for you. I find I can be very pro-active.*

Focus group participants described efforts to communicate with and educate providers to ensure their questions and concerns were addressed and potential health problems were avoided. This was no small task, because the women's highly individualized knowledge was sometimes not recognized by providers, who seemed to value a more generalized form of information about disease states and treatments. The women prepared in advance for health appointments by anticipating problems and coordinating assistance and transportation.

## 6.6 Facilitators to Accessing Screening

The focus group participants also described positive interactions with the HCS and instances where screening was successfully obtained. These were important anecdotes because they highlighted resources that facilitate access to cancer screening and health care in general. From these stories, we can extract valuable ideas for specific recommendations.

Some women had connected with facilities that were uniquely structured around the needs of women with a variety of disabilities. Several had also found individual providers who had expertise and great sensitivity to their health needs. These settings and providers offered longer appointment intervals to reduce pressure, provide ample time for provision of care, and open space for discussion of health issues. Attendant services and special equipment were sometimes available to facilitate procedures such as cervical screening.

*I get screened every year [for breast cancer]... I'm very vigilant about breast cancer screening because my mother died of breast cancer. Where I go, it is accessible. I take my walker; I can get into the building. People are very accommodating. Not everyone has problems with accessibility but they know I do. They pull out a chair for me to sit in. I'm very pleased with the facility.*

*Joining [a dedicated health facility for people with disabilities] was very good for me. Before then I went to doctors in hospitals or in a clinic. But I was more mobile then, I could get out of my wheelchair and they'd help me. But for a few years I couldn't go. I feel very comfortable going [there]. The doctors I've dealt with, and the nurses are amazing. One lady comes to help you dress. She'll ask if I can walk and she lets me take her arm. This takes the stress off me for going to the doctor. The last time I wasn't that comfortable. I found him rough. It was painful after that getting Pap smears without pain.*

According to participants, positive attitudes and interpersonal styles of health providers can make an important difference by creating a welcoming, rather than intimidating, experience. Women sought care with confidence when they saw that their primary care provider had bothered to learn more about their unique health needs. They appreciated opportunities to ask questions, contribute their own opinions, and discuss merits of treatment options. Anecdotes told by participants indicate that they appreciated providers who treated them with respect and recognized their acquired self-care knowledge.

Over time, most of the women had accumulated knowledge about their health and bodies. They had general and specialized knowledge of their health issues that reflected a blend of "textbook" information and long term experience with the unique responses of their own bodies.

*I don't rely on my doctors for up-to-date information. I very much rely on what I hear from others. And the radio and Internet. You see posters ... For me it's reflexive because if I hadn't been that way from a young age – we were all supposed to be dead. So there you go!*

## 7.0 Preliminary Recommendations

**More places with accessible exam tables and screening technology and on-site attendant care that are clearly publicized to the disability community.**

**More personnel to address disability-related needs and anxieties prior to screening procedures**

*Participant: Just having more places have accessible exam tables would be nice. It would be nice to have options of where to go.*

*P: Also, the Canadian Breast Cancer Foundation could make public announcements for women with disabilities*

*P: It would be good to have people speak to people's anxieties. Putting out front everything they could offer could save time. They should let people know if they have accessible exam tables beforehand, etc.*

*P: Maybe we can more written materials for people with disabilities such as phone numbers.*

*Peer Facilitator: I think it would make a difference if people ask the questions at the time of intake: what do you need when you come here? Do you have an attendant? And so on and so forth. That way you know where you can go and what services are available there.*

**Strategic health messaging with disability-positive images and specific information for women with disabilities to support self-advocacy in accessing screening.**

*Facilitator: I wanted to ask a question just before we move on. Around sources of information, would it make a difference to you if the information spoke to you as a woman with disability?*

*Participant I: I think it would be a supportive tool. If there are illustrations on the pamphlet or if there are different options listed for people with disabilities.*

*Participant II: It would make people feel included. Maybe that would have an effect on people taking more authority at the doctor's office.*

### **On-site health education sessions for women with disabilities on screening guidelines, procedures and body-specific strategies for optimal care**

*P: I wouldn't mind seeing what it looks like so I can develop options about how to do it best.*

*Nurse Clinician: You might want to come to our breast health awareness night in December. They chose to do that because women could wheel around the breast centre and look at the machines. You just need to call...*

*P: That sounds good. Because being there for the first time and having no idea what is going on is never a good idea.*

### **Disability Training for Health Care Professionals and clinical staff at all levels on appropriate and clear communication, compassionate behaviour and best practices**

*The people you're interacting with need really good training on how to interact with people with disabilities.*

*It's important to educate the doctors nurses and technicians, that each of us is a whole person. We need to look after our whole self, whether that involves cancer screening or mental health. We need to be seen as individuals – disabilities affect everyone in different ways. The best thing is to have open communication.*

### **Creating safe and positive spaces for women with disabilities from LGBTTO communities, marginalized ethno-cultural communities, low socio-economic status and various ages**

*If there is a specific day for disabled people to screen for cancer that might be good.*

*If there were a way for us to learn about our bodies – like classes.*

### **Patient-centred and integrated preventive cancer care that includes more options and less coordinating work for patients**

*"In my ideal world, I would have a certain place for accessibility where I could go and be examined properly. That's me."*

*"And house calls being an ongoing part of the system. Doctors and nurse practitioners. I know they exist and develop tests that everyone would have to determine a course of action on a frequent basis so it would be easier to have that security. And if you're not currently at risk you could relax and if you are at risk you'd have people trained on how to work with you."*

## 8.0 Conclusions and Next Steps

Interestingly, the tensions that exist within the broad scope of research between community-based and traditional research methods were reflected in the early stage of our group process. The disability rights activist members of the research team expressed that they experienced an initial reticence about joining with nursing professionals and academics to do research about disability health. Their past experiences of such engagements were often challenging and not always respectful of the particular expertise that lived experience as disabled women produces. The academic and health care professionals involved in the research were very much aware of this history, and also of the current inadequacy of health care research that uses old methods that do not engage with the community.

As it is our goal to unpack the day-to-day navigations of disabled women in the health care system, exploring and documenting both barriers and facilitators, it was necessary to find a way to do this research differently. Ultimately, we found that as a research team, this form of collaboration between community activists, professionals and academics can actually work. Our analysis of data contrasts traditional approaches by looking at issues of how bodies are valued and under-valued, and what the impact of time, space and economic and structural realities are on disabled women's health care experiences. Perhaps most importantly, we are looking at what has worked well, and how we can build on the things that already facilitate health care access.

Through the entire research process both within our research team and through the inclusion of multiple women's voices from diverse milieu we have fore-fronted disabled women's expertise about their own bodies and experiences. With this focus, we reinforce our belief and our starting point that disabled women need to be supported as active agents in their own health care. Too many reports sit on shelves. The Gateways Project wants to maintain the momentum, energy and community spirit of this project by entering a phase of knowledge translation that is innovative, participatory and creative.

## 9.0 Appendices

<b>Appendix A</b>	<b>Recruitment Flyer</b>
<b>Appendix B</b>	<b>Participant Questionnaire</b>
<b>Appendix C</b>	<b>Focus Group Protocol</b>
<b>Appendix D</b>	<b>Consent Form</b>
<b>Appendix E</b>	<b>Counselling and Support Services</b>
<b>Appendix F</b>	<b>Community Organizations that Serve Women with Mobility Disabilities</b>
<b>Appendix G</b>	<b><i>Navigating Health Care: Gateways to Cancer Screening, Disability and Society, 2008 (in review)</i></b>