

CILT's Peer Links

Volume 9, Issue 3
Spring 2008

Gateways to Cancer Screening: A Participatory Needs Assessment of Women with Mobility Disabilities

Background: Cancer and Screening

Early detection and screening are seen as ideal areas of intervention in the cancer control continuum. For women with disabilities, access to screening and support has been a challenge due to multiple barriers:

- Women with disabilities have the same biological risks as other women for developing all cancers.
- These barriers include lack of knowledge among these women, neglect on the part of health care providers, and physical access barriers (Welner; 1998).
- Women with disabilities, in particular those who are older, are less likely to receive regular Pap tests and mammograms (Nosek & Howland, 1997).

How We Got Started

The Centre for Independent Living in Toronto (CILT) 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 Mount Sinai Hospital and Canadian Cancer Society in order to write a proposal and seek funding.

Funding and Support:

The project is funded and supported by the Canadian Cancer Society, in particular, the Diversity & Cancer Control teams. They provide in-kind for the project, and ensure that the project reflects the diversity that exists in Toronto. Recommendations from the research will be carried forward in a meaningful and sustainable way.

Who are the team partners?

- Centre for Independent Living Toronto (CILT) Inc.
- Mount Sinai Hospital, Marvelle Koffler Breast Centre
- Canadian Cancer Society
- University of Toronto, Faculty of Nursing

Also on our Advisory Group:

- Ismaili Cancer Support Network
- Anne Johnston Health Station
- Springtide Resources (formerly Education Wife Assault)

What is the Gateways Project?

The Gateways Project is a community-based participatory project that was carried out in the form of a qualitative needs assessment. We aimed to explore the experiences and needs of women with mobility disabilities when they access breast, cervical and colorectal cancer screening.

What is a Qualitative Needs Assessment?

A Needs Assessment is an exploration of the way things are and the way that they should be. In qualitative needs assessments, the aim is to gain personal insight from individuals or groups as to the nature and impact of a particular situation (Kaufman, R & Fenwick, W. Needs Assessment: Concept and Application, Educational Technology Publications, Englewood Cliffs, New Jersey, 1979).

Initially, the Gateways Project working group considered taking the qualitative description research approach. Historically, researchers did not include members from the disability community in their work. The project team strongly believed in inclusion and consensus-based decision making at each stage of the project. We also wanted an action component, which therefore moved us to Participatory Action Methodology.

What is Participation Action Research?

We chose this method of research because it included participation and most importantly, an action component. The action component is where we take the knowledge from the focus group participants and transfer it to cancer screening organizations, raising awareness among service providers that could possibly

lead to informed changes in practice. Focus group participants would also feel empowered through shared discussion and the fact that their voices were being heard and listened to. It was decided by the research team that for this particular study, the Gateways Project, focus groups would be the best way to collect data with peer facilitators asking the questions, because focus groups allow participants to build on each other's ideas that may not be obtained in a one-to-one interview. Approval was obtained by the Research Ethics Board at the University of Toronto, for consent forms, letters of invitation to organizations who provided support to women with mobility disabilities, recruitment flyers and research protocol.

Community Outreach:

We deliberately attempted to hear from women from diverse communities, including women of colour, lesbian, bisexual, trans-gendered and trans-sexual 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 sociocultural demographics, and these aspects of life impact the experience of disability and one's relationship with the healthcare system.

How We Carried Out the Needs Assessment:

In total, five focus groups were conducted which were led by peer facilitators, with individuals who self-identified as women living with mobility disabilities. In order to participate in a focus group, each participant had to meet the screening criteria: no previous history of breast, cervical or colorectal cancer; they had to be at least 18 years of age and living in the GTA. Women were able to discuss their experiences with cancer screening and share insights, barriers and facilitators of screening.

How the Focus Groups Were Conducted:

Each focus group was held at an accessible location, two at CILT, two at the Canadian Cancer Society, and we were asked to do one in the Region of Peel. 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.

Ground rules for confidentiality were mutually discussed by everyone before the actual focus group began. All participants were provided with attendant services, if required, and light refreshments.

Women's Health Presentation:

At the beginning of each focus group, before getting into the actual focus group questions, a small Powerpoint presentation was given on Breast, Cervical and Colorectal Cancer information with the current screening guidelines set out by Cancer Care Ontario.

Peer Facilitation, Process Checking & Take-Home Info:

Each focus group had two on-site transcribers using laptop computers, all focus group sessions were audio taped, and information provided by the participants was recorded on a flipchart as a method of validation.

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.

Each participant received a Canadian Cancer Society (CCS) bag with small gifts, and information about CILT, CCS, Cancer Care Ontario, Sherbourne Health Centre and cancer screening.

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.

Key Themes and Focal Points:

“Bodies” in Relation to Screening:

One theme we noted across all the focus groups was how participants foregrounded 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 transcripts from the focus group sessions, the embarrassments, vulnerabilities and bodily predicaments experienced by the women during screening were quite evident.

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.

Barriers Created to Access by the Health Care System:

Data collected from the focus group participants highlighted repeatedly that the health care system 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)

Barriers to Access External to the Health Care System:

The Health Care System 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.

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 well-being. 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.

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.

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.

Facilitators to Access Screening:

The focus group participants also described positive interactions with the HCS and instances where screening was successfully obtained. 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.

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.

Highlights of the Report & Recommendations:

1. More places with accessible exam tables and screening technology and on-site attendant care that are clearly publicized to the disability community.
2. Strategic health messaging with disability-positive images and specific information for women with disabilities to support self-advocacy in accessing screening.
3. More personnel to address disability-related needs and anxieties prior to screening procedures.
4. On-site health education sessions for women with disabilities on screening guidelines, procedures and body-specific strategies for optimal care.

5. Disability Training for Health Care Professionals and clinical staff at all levels on appropriate and clear communication, compassionate behaviour and best practices.
6. Creating safe and positive spaces for women with disabilities from LGBTTTQ communities, marginalized ethno-cultural communities, low socio-economic status and various ages.
7. Patient-centred and integrated preventive cancer care that includes more options and less coordinating work for patients.

To read the full report, please visit
www.cilt.ca/peersupport/Gateway_project.aspx

Out From Under: Disability, History and Things to Remember

The Royal Ontario Museum (ROM) is pleased to present a ground-breaking exhibition "Out From Under: Disability, History and Things to Remember" - April 17th to July 13th, 2008. Enter via the Bloor Street West Entrance of the Michael Lee-Chin Crystal. Organized by the School of Disability Studies at Ryerson University and the ROM. This exhibit chronicles the struggles, alliances and setbacks faced by people with disabilities in Canadian history and illuminates the proud history of resistance and survival.

Catherine Frazee states "Disabled people don't seek merely to participate in Canadian culture - we want to create it, shape it, stretch it beyond its tidy edges."

Turning Point: Summer 2008 Program in Toronto for Youth Who Have ABI

Turning Point is for young adults 16 to 25 years of age who have and Acquired Brain Injury and who want to become more independent and who are motivated to work on skills related to independence and are thinking about next steps to living on their own, and who also have the ability to participate actively within a group setting.

Turning Point takes place for six days and five nights - July 6, 7, 8, 9, 10, and 11, 2008 at Ryerson University Residence, Pitman Hall, 160 Mutual Street, Toronto. The cost is \$450.00 for five nights. Financial assistance is available.

Program topics include: social skills and independence, getting around the city, recreation and leisure and problem solving. Activities include community outings, making meals and final party planning.

For more information, call Julie Osbelt at (416) 425-6220, extension 3298.

Stepping Up

Stepping Up focuses on life skills and community volunteering skills for youth and adults with a variety of special needs and serves to strengthen the relationships among participants of the program and with our community. The program provides our participants with the opportunity to build on and learn new life skills, such as nutrition, self-awareness, city access, money management, and career building in a safe and supportive environment.

The program is open to youth and adults sixteen years of age and older, who are currently living independently or are seeking greater independence in their lives. Stepping Up has a weekly cap of 20 participants and operates with 3 highly qualified staff. The program will run for seven weeks, from June 30 – August 15, 2008, with participants open to attend from 1-7 weeks. There are financial accommodations available to those who qualify.

For more information contact Dagney Gardiner, Program Director, A&I Services, City of Toronto, Etobicoke Civic Centre by email dagneygardiner@hotmail.com or by telephone at 647-887-2097.

EMPLOYMENT OPPORTUNITY

Young Women's Program, Youth Leader

Springtide Resources (formerly Education Wife Assault) is an organization committed to ending violence against women through education and training.

Springtide is inviting applications from young activists who have creative ideas about how to engage their peers and raise awareness about issues of violence and oppression of young women.

You bring:

- an idea for a project;
- enthusiasm, energy and a desire for social justice;
- understanding of interpersonal relationship violence and systemic

- oppression;
- an ability to work on your own and with a team;
- strong verbal and written communication skills;
- an ability to be organized and manage your time well;
- some experience public speaking or facilitating groups would be an asset.

We will provide:

- women who are actively pursuing an end to violence against women in our communities, who would be co-workers and mentors;
- years of experience in community development and social justice;
- funding for your project;
- a supportive, feminist, queer positive work environment.

The Youth Leader is a contract position for \$16.00/hr, 35 hours per week for 12 weeks.

To Apply:

You must be a young person who identifies as woman or trans woman, and between the ages of 17 and 25.

Send us your resume and a letter that describes your project in detail; including why it is different and innovative. The interview committee will choose 3 to 5 applicants to come in and make a small presentation of their idea.

You can send your application by email, snail mail or fax. We appreciate your interest, however only those applicants selected for an interview will be contacted.

Posting closes: 5:00 pm, Monday, May 5, 2008

Contact Information

Young Women's Program Hiring Committee
215 Spadina Avenue, Suite 220
Toronto, ON M5T 2C7
Email: margaret@womanabuseprevention.com
Fax: 416-968-2026

Please make sure you review the attached sheet for information about the criteria for project ideas (SEE BELOW).

Young Women's Program, 2008 Criteria for Project

The project must address the issue of violence against women. Violence against women for the purpose of this project encompasses issues of systemic oppression and interpersonal relationship violence:

1. Systemic oppression – body image, racism, ableism, homophobia, transphobia, etc.
2. Interpersonal relationship violence – intimate partner violence including sexual violence, partner abuse, dating violence, etc.
3. The project should include diverse perspectives and lived experiences. For example if your idea is to address homophobia, ensure that the lives of diverse queer youth are represented.
4. The project has to have a beginning and end. The organization does not have the resources to fund an ongoing program.
5. The project must involve engaging youth in the community. This can be through things like presentations, working groups, peer education groups, workshops, popular media events, etc.