Women with Disabilities & Breast Cancer Screening:

Identified Problems, Strategies and Recommended Next Steps

An Environmental Scan 2013

Prepared for the
Canadian Breast Cancer Network
Written by Doris Rajan on behalf of
DisAbled Women's Network Canada

DAWN RAFH Canada
Leadership, Partnership and Networking
Leadership, Partenariat et Réseautage

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Canadian Breast Cancer Network
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Prepared for the Canadian Breast Cancer Network (CBCN)

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About DAWN-RAFH Canada
DAWN-RAFH) Canada is a national organization of women with various disabilities with a mandate to represent the concerns of disabled women to the women's and disability sector and the Government of Canada and to be their voice. DAWN-RAFH Canada's mission is to end the poverty, isolation, discrimination and violence experienced by women with disabilities. We are working to ensure women with disabilities get the services and supports that they need.

About CBCN
The Canadian Breast Cancer Network (CBCN) is the only national survivor-driven and survivor-focused breast cancer organization in Canada. CBCN advocates for the improvement of services and access to optimal care for breast cancer patients. CBCN is the national link between all groups and individuals concerned about breast cancer.

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Background

In November 2009 the Canadian Breast Cancer Screening Initiative Underserved Populations (CBCSI) Working Group, held a two-day event entitled “Reaching all women: Sharing and building on evidence informed practice to meet underserved women’s needs”. Women with disabilities represented one of the four target groups along with newcomers and immigrants, First Nations, Inuit and Métis women, and geographically isolated women. At the conclusion of these two- day meetings it was determined that there was a need for specific policy guidelines, data collection on the needs of these populations and their screening rates, an inventory of existing resources, training and capacity building for both the women and relevant service providers and that any work to be conducted would need to involve the women representing these underserved populations.[1]

In follow- up discussions with the Public Health Agency of Canada, the Canadian Breast Cancer Network (CBCN) originally wanted to conduct focus groups to examine the issue of access to screening for women with disabilities. However it was decided that some preliminary work needed to occur prior to any primary research in order to better understand the challenges that have already been identified and what literature and resources currently exist, so that the learnings could be used on the development of future interventions.

Given that the DisAbled Women`s Network (DAWN) - Réseau d'action de femmes handicapées (RAFH) Canada is the only national organization in Canada which represents the interests and concerns of women and girls with disabilities, the Canadian Breast Cancer Network contracted DAWN-RAFH Canada to conduct the review of relevant projects, resources and literature related to the issue of access to breast cancer screening for women with disabilities. DAWN-RAFH Canada welcomed this opportunity to grow their relationship with the CBCN as well as build their partnerships in the larger women`s health equity sector.

Methodology

TERMS OF REFERENCE

The Purpose
The primary purpose of this Environmental Scan is to identify any reports, research papers, resources/tools and projects that have been developed related to the issue of breast cancer and women with disabilities, in order to develop a comprehensive understanding of the challenges, needs and strategies for increasing access to breast cancer screening for women with disabilities in Canada.

The Questions
In order to accomplish this task, an examination of materials and initiatives was guided by the following four questions:

1. What is known about the nature and prevalence of breast cancer for women with disabilities in Canada?

2. What information is available on the challenges and accessibility of breast cancer screening practices for women with disabilities throughout Canada?

3. What are some ideas and recommendations for addressing these challenges?

4. Where should the future direction of work be in the area of increasing access to breast cancer screening for women with disabilities in Canada?

Parameters & Scope
Health research and community health work specific to the needs of women with disabilities has been intermittent or sporadic over the years, largely due to the lack of sustainable funding for research and project development. This has resulted in an ebb and flow of research and project implementation over the last two decades. Not only has there been limited research, policy and program development in this area, but much of the work in Canada related to health and women with disabilities took place in the 1990's and thus requires updating.

More recently there has only been limited work conducted in the area of general health equity for women with disabilities in Canada, which further limts information specific to cancer and women with disabilities.

The parameters of this review identifies and examines work that;

- ✓ Has taken place between 2002 and 2012;

- ✓ Is Canadian, with some references to American and United Kingdom literature due to socio-economic and cultural similarities;
- ✓ Focuses on women with all types of disabilities[1] with an expansion to men when pertinent information is absent yet applicable for women with disabilities; and

[1] The Breast Cancer Screening Initiative felt that given the diversity of disabilities that exist, this review should be limited to physical disability. DAWN-RAFH Canada however is an organization for all women with disabilities who recognizes the importance of understanding the intersection of various experiences of marginalization including the reality of multipe disabilties for many women.

- ✓ Focuses on breast cancer, with some references to other cancers and general health equity when deemed relevant.

Keywords

Given these parameters, specific keywords and precise combinations were used to guide the electronic search process. In narrowing this search we also needed to ensure that we were always pursuing the connection between; a) women with disabilities and b) health, cancer and breast cancer.

Since the primary purpose of this review s to consolidate information on the challenges women with disabilities experience in accessing breast cancer screening in order to identify promising practices for addressing those challenges, prioirty was given to non-academic, more community-based information. Community-based research usually uses applied research techniques and prioritizes knowledge translation and mobilization. By definition community based research; a) initiates topics of practical relevancy to a particular community or population, b) requires the equal collaboration of community members with researchers at all stages of the research process and c) is action-oriented. Community-based research intentionally seeks practical information that can be used to make positive changes for the community concerned.[2]

The following combinations were sequentially applied:

1. Women with disabilities, breast cancer, screening, Canada
2. Women with disabilities, breast cancer, screening
3. Women with disabilities, cancer, screening, Canada
4. Women with disabilities, cancer, screening
5. People with disabilities, cancer
6. Women with disabilities, health, access, Canada
7. Women with disabilities, health, access
8. People with disabilities, health, access, Canada

The Process

Reports, articles, resources, guides and projects/initiatives were located through the following avenues:

Accessing Major Search Engines, such as:

- Google http://www.google.ca/ The paradigmatic internet search engine, focus on Canadian sites.
- Google Adword Keyword Tool
- Google scholar

Accessing university based computer library centre databases.
This was conducted to a much limited degree due to the fact that the focus was on community-based work conducted or commisioned by women with disabilities.

- Social Science Abstracts, SocioAbs, Sociological Abstracts, and WorldCat.
- Bibliographies from key peer-reviewed journals, books, papers, and dissertations in this area of study (2002-2012)

Requests to Community-Based Experts
Given the dearth of published information on women with disabilities and access to breast cancer screening, what proved to be the most effective avenue for accessing the most pertinent materials and information was through contacting researchers, community developers and social advocates who have specifically initiated work in this area. A few relevant groundbreaking projects have been developed and implemented sporadically over the last decade resulting in a small community of women in Canada, the majority of them women with disabilities, who have a distinct expertise in the area of cancer, health and women with disabilities. These indivdiuals were asked to refer us to any information, individuals and and/or resources that they might know of related to this issue.

The aim eventually is to collect hard copies of all relevant documents in order to formulate a hard-copy filing system on this issue to be housed at DAWN-RAFH Canada's offices.

The information identified for this Environmental Scan is presented in the following two categories:

1) The Nature of the Problem and 2) Strategies and Promising Practices.

The Results

1. The Nature of the Problem

As noted in most of the studies included in this report, there are only a few academic research papers and community-based projects that specifically examine the barriers to breast cancer screening for women with disabilities. However, some of these are landmark Canadian studies with important findings that should serve as the foundation for future community development and knowledge mobilization efforts. Before examining work specific to the issue of women with disabilities and breast cancer screening, it would be useful to highlight some general information on access to healthcare for people with disabilities in order to identify barriers that might also be relevant in the cancer screening process.

a. General Health Care Access for Women and Men with Disabilities

A large scale national study in the United States found that people with intellectual disabilities experience exceptional challenges to staying healthy and getting appropriate health care, and many feel excluded from public health promotion and prevention campaigns.[3] Similarly, a Canadian national survey found that adults with disabilities reported more than three times as many unmet health needs as the non-disabled population.[4] Further people with one type of disability, (e.g. intellectual disabilities) are more likely to have additional disabilities(e.g. physical, mental health, communication disorders etc.) making them more vulnerable to poor health and often leading to difficulty in communicating the nature of their health issues. In addition, poverty rates are exceptionally high among people with disabilities, creating additional barriers to to nutrition, medical care and other resources. A disproportionate number of women with disabilities live in congregate care living arrangements such as group homes or institutions where they experience high stress factors and are at a higher risk of infections associated with ulcers and gastric cancer.[5]

International and national studies have demonstrated that people with disabilities, particularly women and those with intellectual disabilities have higher rates of certain types of cancer and death related to cancer. For example, a study on breast cancer revealed that the rate of death for women with disabilities was higher than for those without disabilities even though both groups were treated for early breast cancer.[6] Women with intellectual disabilities are at a greater risk for leukaemia, uterine and colorectal cancers.[7]

There has been a move from institutional to community care over the last few decades for people with disabilities and generic health and social services have not been able to adapt to meet this population's needs. People with disabilities' segregation from mainstream society through institutionalization coupled with a lack of access to health information has meant that health care facilities have not been exposed to the needs of people with disabilities and thus are not knowledgable on how to meet those needs. In addition the kinds of supports (financial, attendant care, affordable and accessible housing, etc..) people need to be properly included in the community are either not available or are inadequate. Health care providers have demonstrated difficulties in providing quality care to patients with disabilities.[8]

Because people with disabilities frequently have limited access to education and/or low literacy/comprehension rates, health promotion resources and campaigns are often ineffective for them.[9] It has also been found that the health sector tends to neglect health promotion activities aimed at people with disabilities.[10] Perhaps as a result of this, women with disabilities are less likely than women without disabilities to receive pelvic and mammogram exams on a regular basis and are thus at a higher risk for delayed diagnosis of breast and cervical cancer.[11]

An American study that examined access to health care for girls and young women with disabilities noted that many women with disabilities have had negative childhood experiences with the medical profession particularly during "teaching" rounds in hospitals, including "public stripping and objectification of their bodies in front of doctors without regard for modesty and privacy". These horrific experiences are "likely to cause girls and young women with disabilities to see health care providers as enemies rather than allies".[12] Although this article notes architectural barriers to health care, such as narrow doorways,

inaccessible toilets and inaccessible examining tables, it emphasizes that attitudes represent the most damaging barriers. For example health care providers often refuse to treat a woman with a disability or may provide treatment based on misinformation.[13]

Another important barrier that was identified in accessing health care for girls and young women with disabilities was that parents may be overprotective and assume that they have to take the lead in their child's health care. This may lead to young women not getting the health care they need because they are not encouraged to be proactive about their health care and/or may hide health conditions because they do not want their parents to know about them.[14]

b. Barriers to Breast Cancer Screening for Women with Disabilities

The few academic papers/studies that do exist can be found periodically in the international context, with most tending to focus on one type of disability and breast cancer. These articles are located in medical, health and disability specific research journals. Most of these studies highlight the fact that while we know that breast cancer is one of the most prevalent cancers affecting women and that early detection through screening greatly improves survival rates, women with disabilities are not being screened thereby delaying diagnosis and potentially leading to adverse outcomes.

The Inserm Research Unit in France noted that women with disabilities infrequently undertake breast cancer screening and thus are at risk of late-stage breast cancer. Their study surveyed 600 general practitioners in Provence, France with the purpose of identifying the barriers that women with disabilities experience when attempting to access breast cancer screening.[15] The findings of this study indicated that general practitioners felt discomfort when treating people with disabilities and felt they needed more assistance with both women with mental and physical disabilities. They also noted communication difficulties in dealing with women with disabilities.

Disability specific work includes a study on the barriers to cancer screening for women with mental health problems in Australia, which found that the environment and the location of cancer screening facilities greatly influenced effective access for this population.[16] Another Australian study examined the fact that women with intellectual disabilities who are living longer and are often *nulliparous* -- never having given birth -- are at increased risk of developing breast cancer. The women surveyed in this research lived in group home settings with only one third of the group studied participating in regular breast examinations in an environment with little supports and health care professionals being remiss in promoting the importance of breast cancer screening to this group of women.[17]

There is more information on the general health status of people with disabilities, some of which indicates that women with specific types of disabilities are at an increased risk of breast and other forms of cancer. An American study that set out to identify the barriers for breast cancer screening by mammography for women with cerebral palsy, found that women do not engage in this early detection health practice, thus leading to a delay in treatment. Key barriers identified in this study were accessible information, difficult to obtain transportation to get women to the screening facility and the lack of support or assistance while there. [18]

A study by the Canadian Partnership Against Cancer acknowledges that there has been little research on disability and cancer in Canada, but acknowledges that international research demonstrates that people with disabilities may be greater risk of specific types of cancer, less likely to be screened and have poorer prognoses and survival rates.

In addition this study makes a distinction between people with "pre-existing disabilities" and those who experience disabilities as a result of cancer or cancer treatment.[19]
Those with pre-existing disabilities experienced delayed detection and diagnosis and complicated treatment experiences that related to cancer care providers having limited knowledge of cancer and its interplay with specific "pre-existing conditions". Of those people who became disabled as a result of cancer or treatment they had acquired new impairments including facial paralysis, hearing and mobility

impairments, difficulty eating and drinking and mental health conditions and weakness and fatigue.[20] This study also found cancer care providers had diverse perspectives on disability with most viewing disability as impairment and some understanding that societal factors "disable" people.

The Canadian Breast Cancer Screening Initiative Underserved Populations Working Group noted that what was lacking in screening services were: competencies at the
service level for health care screening staff, procedural guidelines and equipment that is sensitive to the needs of women with a diversity of disabilities, relevant educational and promotional resources and an inventory of resources that have already been developed.[21]

A research study entitled "Proposals to Facilitate Access to the Quebec Breast Cancer Screening Program for Women with Activity Limitations" looks at 25 proposals or projects that examined access to the Programme québécois de dépistage du cancer du sein – Quebec's breast cancer screening program [22] This study applied a systematic process for examining characteristics of the screening process that both hinder and increase access to breast cancer screening programs for women with various types of disabilities. The research highlights the fact that women with "activity limitations" encounter barriers at various points of contact with breast cancer screening programs and that there are no organized or procedural measures put in place to best serve this population. In reference to barriers this study draws on work in Europe, the United States and Australia and identifies four different types of barriers related to; 1) personal factors (e.g. communication difficulties and physical capabilities of compliance to mammogram procedures), 2) relational factors (e.g. fear of health care professionals), 3) organizational and systemic factors (e.g. lack of time) and 4) environmental factors (e.g. transportation).[23] This study also describes a number of key barriers to keep in mind; how the mammography procedure may "trigger fears connected with difficult aspects of women's lives (e.g. body image, past negative experiences) and that for some women with "complex profiles" such as chronic illness or behavioural problems, the procedure can be particularly difficult."[24] The mammography process involves unusual positioning of one`s arms, chest and breasts which may be uncomfortable and painful for women with particular types of chronic illnesses and frightening and anxiety producing for women with psycho-social disabilities or those who have been sexually or physical abused.

Two organizations, Echo: Improving Women's Health in Ontario & the Centre for Community Based Research, consulted women with disabilities with the goals of increasing awareness of issues and best practices, exchanging information to increase access, and engaging stakeholders to develop strategies in expanding access to breast cancer screening for women with physical disabilities. The discussion identified very specific types of barriers:

- Lack of monitoring of the *Accessibility for Ontarians with Disabilities (AODA) Act;*
- Treating an illness vs. treating the person;
- Need to maintain equipment e.g. automatic doors;
- Flexibility in screening test for example, ultrasound vs. mammogram;
- If the physician is on vacation, others won't provide coverage;
- Difficulty getting on the table;
- Fear of doctors, i.e. women not knowing what exactly the procedure is and what happens after;
- Negative experiences in the past - women not wanting to go for ongoing services;
- Walk in clinics do not provide referrals, advice or continuity of care for women with disabilities; and
- Must have pre-existing gynocological condition to access specialty clinic.[2]

[2] Adpated from the notes: Echo: Improving Women's Health in Ontario and The Centre for Community Based Research. (2011) *Knowledge Translation for Cancer Screening Projects*. Toronto: Echo/CCBR. Page 6.

There are two impressive Canadian initiatives that offer an intensive examination of the issue of women with disabilities and access to breast cancer screening:1) Access to Breast Cancer Screening Programs for Women with Disabilities, which evaluated the accessibility of Quebec programs with a focus on the Montreal area[25] and; 2) the Greater Toronto Area`s Gateways to Cancer Screening project, which set out to identify the barriers faced by women with mobility disabilities in accessing breast cancer screening and services, and to identify gaps in services[26].

The Montreal based study notes that women with disabilities are living longer, into menopause, and are consequently at higher risk of breast and uterine cancers. The report highlights the fact that women with disabilities experience a lack of access to health care in terms of health awareness and inaccessible facilities. If women with disabilities do make it to screening facilities and are able to participate, health care providers tend to medicalize and/or pathologize them, with the result that they are less likely to participate in regular screening:

> Furthermore, health care providers do not encourage women with disabilities to get screened focusing instead on the medicalization of disability and not on the health conditions they face as women. [27]

This study also sheds light on attitudinal barriers, such as screening staff addressing family members or attendants rather than the woman with the disability. Staff were also uninformed about the realities facing women with disabilities. For example staff suggested that women without family members or friends to accompany them to screenings should rely on paid support. This is problematic because it is either costly or cuts into the number of hours per week that a woman can get their government funded attendant care workers. Given that Deaf women do not use speech to communicate and that women with intellectual disabilities may have speech impediments or be either non-verbal or have limited verbal capacities, these two groups of women experienced the most difficulties in communicating with staff.[28]

For the Gateways project, the research team – made up of both academic and community-based researchers, many of whom were women with disabilities, adhered to a conceptual framework guiding the research that understood how bodies are valued and the systemic physical, attitudinal barriers and the broader socio-economic barriers that impacts many women's experiences in accessing breast cancer screening. In addition the expertise and experience women with disabilities had regarding their own bodies was placed front and centre through the entire research process.[29] The research noted that negative experiences that women with disabilities had with the medical profession had a great effect on women's attitudes, expectations and behaviour when considering screening. Women who participated in focus groups discussed the false assumptions health care professionals made about their abilities and who they were as people as this quote from a research participant demonstrates:[30]

> 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 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.[31]

The report notes that there are five categories of barriers for women with mobility disabilities in accessing breast cancer screening services; 1) physical, 2) communication, 3) attitudinal and 4) economic.

The physical barriers included; mammogram machines and scales that require standing or specific positioning and inaccessible exam tables. As the report explains, "women may find it painful or physically impossible to position appropriately on basic medical equipment"[32] Some women with mobility disabilities also have hearing or vision impairments and thus had different communication requirements. Further information is not available in alternative accessible formats.

Economic barriers may keep women from accessing health care. The researchers noted that the additional time it might take to serve a woman with a disability may serve as a financial deterrent to health

care providers.[33] Since health care centres charge a fee for each patient that receives service, providers benefit from fast and efficient service provision because they can then increase the number of patients seen in a day.

The unreliability of accessible transportation systems was another barrier to screening often making women late for appointments and missing pick-ups. Lastly assistance with breast cancer screening by attendants is needed yet there are specific hours allocated a week for much needed attendant care services, (e.g. for primary care) and accompanying someone to a health care appointment may go against an attendant's job description and/or approved schedule.

2. Strategies, Promising Practices and Resources

The majority of the academic studies that were examined focused on identifying the problem of inaccessible screening processes and tended to state the obvious in their conclusions around what should be done about this, i.e. the need for education for health professionals, accessible equipment and appropriate outreach and health promotion techniques aimed specifically to reach women with disabilities.

Other more community-based research studies and/or projects that were examined in this review, in addition to outlining the nature of the problem of general access to health care and more specifically the barriers to breast cancer screening for women with disabilities, they usually also offered recommendations and in some cases detailed information on types of promising practices.
In this report "promising practices" are defined as those procedures, systems and/or interventions which women with disabilities themselves identified and recommended in the research projects included in this review.

The more recent Canadian projects emphasize the need for universal access, that is women with disabilities should have access to the total breast cancer screening process "as any other woman receives"[34]
The following section shares these findings and also presents some training resources and materials that have been developed.

a. Recommendations and Promising Practices

(1) Adapting the Physical Environment – Buildings and Equipment

Most of the studies that examined the barriers that women with a variety of disabilities experience when attempting to access breast cancer screening recommended that there was a need to address physical and architectural limitations as well as adapting equipment and/or medical (e.g. mammographic) techniques and procedures. For women with mental health disabilities the recommendation was to situate screening sites in hospital-based psychiatric services.[35]

The Canadian Partnership Against Cancer report also stated the need for improvements in the physical environment of the cancer care system for people with disabilities, but did not outline specific recommendations.[36]

Participants in Echo & Centre for Community Based Research (CCBR) consultation in the spring of 2011 offered some specific recommendations regarding the adaptation of the physical environment:[37]

- Hospital based accessible screening opportunities;
- Funding innovative technology to increase access;
- Accessible facilities for examination tables, barrier-free environment;
- Working devices (e.g., automatic doors that actually work – not "just for appearances"); and
- Back-up systems in cases of emergency – ice storms, power outage, etc.

The Action des femmes handicapées de Montréal's study on access to breast cancer screening in Montreal[38] offers detailed and specific architectural and/or technical changes that would reduce barriers to screening programs. This report shares specific details through an audit of relevant programs in the following areas:

- Location - e.g. how close the program was to a metro transit station or if it was located in a medical clinic.
- Adapted Transit – e.g. drop off/pick up locations
- Parking – in terms of reserved parking for people with disabilities
- Entrances – universal access, i.e. all people should be able to use the same entrances
- Doors – e.g. ease in opening, automatic, etc.
- Signage – accessibility of signs to assist women with a variety of disabilities to find the screening site within a hospital or clinic.
- Waiting and change rooms – accessibility of these rooms for women who use wheelchairs
- Washrooms – location and accessible features, e.g. grab bars, hand dryer at an adequate height, etc.
- Mammography rooms and equipment – e.g. size of rooms, use of the Lorad model equipment that was developed in consultation with women with disabilities or panels that protect people and guide dogs from x-rays and also allow women to communicate with their sign language interpretor behind the panel.
- Accessibility of other examination rooms including biopsy and ultrasound rooms
- Written and audio-visual materials – noting that no materials were in alternative formats thus blocking access to many women with disabiities.
- Consent forms may be difficult for women with intellectual disabilities to complete without support.
- Telephones – e.g TTY availability or location of accessible Bell phones.

The Gateways project recommended that there be "more places with accessible exam tables and screening technology and on-site attendant care that is clearly publicized to the disability community".[39]

The report on the Proposals to Facilitate Access to the Quebec Breast Cancer Screening Programs offered a checklist of best practices in adapting the physical environment and materials including, good signage, clearly communicating which centres are accessible, ensuring that each centre has at least one accessible change room, planning for a woman's visit ahead of time and ensuring that the appropriate equipment and support is available.[40]

(2) Adapting or Proposing New Procedural and Process Practices

The Canadian Partnership Against Cancer report stressed the need for people with disabilities to have more support through patient advocates, cancer navigators, psycho-social support that is sensitive to the needs of women with disabilities, support groups and peer support. In addition this report's recommendations outlined the need for multi-disciplinary teams, improved access to homecare, rehabilitation and family doctors and the need to use the disability community as a resource.[41]

Ideas around procedural changes were also offered by those consulted during the Echo & CCBR session, these include:

- Having a point person who would support individuals to navigate system;
- Use of plain language in resources;
- Check in with individual women (or their advocates or their attendants) ahead of time;
- Having a checklist/other tools for health care providers to ensure they address all the issues;
- Women leave appointments with a follow-up date booked;
- Get staff out of medical facilities and into the community to sites and/or organizations that ask for this information;
- Workplaces need education/awareness to accommodate cancer screening;
- A hub of people who could assist screening (outreach workers); and

- Breast screening should be part of an annual/periodic exam.[42]

The Anne Johnson Health Station located in Toronto is an unique health care facility that has a specific focus on physical, atttitudinal and procedural access for people with disabilities. It was often cited in the literature as a good example or model of promising health care practice for women with disabiities. It was recommended that we examine, build on existing, and develop future models of care in terms of accessibility.[43]

The Canadian Breast Cancer Screening Initiative suggested that there needed to be a nationally accessibile repository of articles, reports, resources and tools that deal specifically withe issue of women with disabilities and breast cancer screening. An assessment guide for screening sites that outlines what a clinic can and cannot do in regards to meeting the needs of women with disabilities was also recommended as a useful procedural tool for screening venues.[44]

The Montreal audit study shared information on how one technician found ways to serve women with disabilities:

> She adapts the screening procedure so that women using wheelchairs could remain in their wheelchairs or she transferred them to a regular chair. This chair also could be used by women who could not stand for long periods of time. Also, the technician could assist women with disabilities who had "uncontrolled movements" (i.e. spasms etc.) or those who had difficulties remaining still. In this case, the technician could hold them forward for the duration of the mammogram. [45]

The Gateways project of the Greater Toronto Area also recommended that there be more personnel to "address disability-related needs and anxieties prior to the screening procedures" and that there be disability sensitivity training for health care professionals around "clear communication, compassionte behaviour and best practices."[46] Other process and procedural recommendations from this project included:[47]

- On-site health education sessions for women with disabilities on screening guidelines, procedures and body-specific strategies;

- Creating safe and positive spaces for women with disabilities from LGBTTQ, immigrant and racialized communities, low income and various ages;

- Provide patient-centred and integrated preventive cancer care that is less complicated to access for women with disabities.

The assessment of Quebec screening programs offered concrete recommendations on improving the process and procedures for women with disabilities. These included:[48]

- ***Providing tools for designated centre personnel*** – i.e. providing a checklist for information that should be provided at the time of booking appointments, systematically asking women if they have "special needs", keep information of women's needs on their screening records, include content on serving women with disabilities in relevant training modules and develop teaching materials specific to the needs of women with disabilities for screening staff.

- ***Identifying and disseminating best practices*** –e.g. Including questions that assess how a site provides service to women with disabilities in their service quality evaluations and examining best practice models for national applicability.

This Quebec study also emphasizes the important role physicians play in disseminating information. The report stressed that the screening process may require complex planning for women with disabilities in terms of transportation and arranging a support person.[49]

(3) Women-centred Disability Sensitivity Training for Health Care Providers

The studies, which focused on women with cerebral palsy, mental health and older women with intellectual disabilities, all concluded that disability sensitive education for health care personnel was necessary in order to deliver more effective and positive breast cancer screening experiences for women with disabilities. [50]

The Proyecto Vision article that was directed to girls and young women with disabilities recommends nurturing adult women mentors for young women so that they are given the opportunity to talk about how to make their own medical decisions and help them better understand breast cancer prevention practices as they pertain to women with disabiities. [51]

The Canadian Partnership Against Cancer states that "cancer care providers need greater knowledge about and better attitudes towards, people with disabilities"[52]

Echo/CCBR consultation participants identified a number of things health care professionals needed to know and/or needed to enact in their work environments:

- Training that focuses on attitudes for health care professionals, right from the start of the screening process;
- Health care providers have to be debunked of the myth that women with disabilities are not sexually active;
- Address the fears and hesitations that health care providers might have when serving women with disabilities;
- Increased sensitivity and knowledge of health care providers about communicating with a range of women, including those with low-literacy levels, who may be non-verbal, have aphasia, are non-English speaking or ESL/EAL [3]
- A communications campaign with flyer-drops in relevant areas, posters in hospitals, clinics etc., email blasts to physicians, media coverage, a sensitivity video and/or use a spokesperson, i.e. a celebrity, someone credible with a disability;

[3] ESL - English as a Second Language is now being referred to as EAL – English as an Additional Language to better reflect the additive nature of learning another language. Please see *Diversity and Equity in Education English as an Additional Language*. Government of Manitoba at http://www.edu.gov.mb.ca/k12/cur/eal/terminology.pdf

- Physicians need to look beyond the primary disability and explore other reasons for symptoms; and

- Bridging misconceptions between health care providers and clients/patients[4]

The Gateways project emphasizes the importance of "postive attittudes and interpersonal styles of health providers" in creating a welcoming, less intimidating and safe environment. The women that they spoke to in this study really appreciated those health care providers who tried to get to know them and their particular health care needs and who discussed the pros and cons of treatment options.[53]

The Quebec project also asserted the need to "mobilize key players" which included the recommendations of; designating a person at the centre who is knowledgable and can bring resources to the screening program on the needs of women with disabilities, sensitivity training for health care personnel, emphasizing to physcians the importance of annual breast cancer screening for women with disabilities and provide physicians with strategies to assist women with disablities to participate in mammography screening. [54]

(4) Outreach and Health/Breast Cancer Awareness & Promotion to Women with Disabilities

The Canadian Breast Cancer Screening Initiative recommended educational/promotional resources that address the different needs of women in terms of "limitations" and intellectual disabilities.[55]

Echo/CCBR participants identified a number of things women with disabilities needed to know and outlined ways to reach women with disabilities:

- Women with disabilities need education about symptoms and what questions to ask of their doctors;
- Assist women on how to find accessible health care clinics/services throughout the province, especially outside of the Greater Toronto Area and any metropolitan urban centres;
- Empower women to know how to care for their own health; and
- Accessible web-based information is needed, e.g., The Centre for Independent Living Toronto's website lists accessible breast screening clinics.[56]

The Canadian Breast Cancer Screening Initiative also recommended communicating to women with disabilities regarding what kinds of accommodations and supports are in place and are not in place.[57]

The Gateways project recommended that there be "strategic health messaging with disability-positive images and specific information for women with disabilities to support self-advocacy in accessing screening".[58]

The Quebec study offered recommendations on "improving the screening program invitation" in ways that will improve access to, and increase women with disabilities participation in, breast cancer screening. These include:

- Highlight the information women need to retain;
- Encourage women to mention any special needs they might have when they make their appointments;

[4] This section was adapted from Notes from - Echo: Improving Women's Health in Ontario and The Centre for Community Based Research. (2011) *Knowledge Translation for Cancer Screening Projects*. Toronto: Echo/CCBR. Page 5-6.

- Encourage women with activity limitations to contact the regional service coordination centre to obtain additional information;
- Standardize program correspondence across all regions;
- Incorporating the strategies considered most useful in terms of helping women understand and make use of the information they are given;
- When sending out invitation letters, staple a list of regional screening centres to the letter;
- For each of these regions identify the sites and equipment available in terms of accessibility.[59]

This study also calls attention to the need to implement targeted outreach to women who live in residential care, for example women with intellectual disabilities, highlighting issues of "information access and the decision-making process with respect to screening mammography".[60]

(5) Policy Recommendations/Reforms

The Echo/CCBR consultation was unique in that it focused on advocacy in the area of policy reforms. A report on the consultation suggested that accessibility needed to be a key part of the accreditation of health care facilities and that "spot-checks on doctor's offices and facilities" should be conducted. In additon they discussed the need for the health care system to abide by and be accountable to the *Accessibility for Ontarians with Disabilities (AODA) Act,* which outlines clear accessibility standards for organizations.The report also suggested providing government incentives to reward facilities that incorporate an accessible design and approach. [61]

In addition, health care facility`s (such as health care centres, hospitals etc) policies should include supporting the provision of funding for accessible medical equipment and a process for phasing out old equipment and replacing it with new accessible models.[62]

The Canadian Breast Cancer Screening Initiative recommended that there be national guidelines/policies regarding cancer screening that include operational guidelines regarding access for women with disabilities for clinical staff, clinics and data collection.[63]

b. Resources & Training Materials

The World Institute on Disability has developed a *Two-DVD Curriculum on Treating People with Disabilities*. This resource is designed to educate individuals and families about how to access health care and to educate health care providers about how to provide appropriate and accessible health care.[64] One DVD addresses access for people with intellectual disabilities and the other focuses on physical disabilities. The DVDs use interviews with individuals, health care providers, parents, and advocates to:

- Explore the views and experiences of people with disabilities and providers in establishing rapport and effective communication,
- Address cultural competence, access and communication issues which often arise in the clinic,
- Identify common myths and stereotypes which interfere with accurate assessment of patients,
- Explain barriers which result in disparities in health care delivery, including physical/architectural, communication, attitudinal and social/economic policy,
- Identify the most common access and accommodation needs of adults with physical, sensory and communication disabilities, as required by the *Americans with Disabilities Act,* and explains feasible, cost-effective solutions,
- Clarify essential principles of quality care in treating people with disabilities.[65]

The DisAbled Women's Network of Ontario has posted a document entitled: *About Mammograms: A Woman's Guide* on their website.[66] It presents information on what mammograms are, how to go about scheduling a mammogram, what to expect, how to prepare for the procedure, and follow-up. While this generic information is useful to include on this website because efforts to share information to women

with disabiities have been limited, this guide is not specifically targeted to women with disabilities and has only a symbolic reference to how the screening process might be different for women with disabilities.

An American organization called Breast Health Access for Women with Disabilities (BHAWD) has as its purpose to increase access to breast health information, screenings and early breast cancer detection for women with disabilities. The organization has developed a resource entitled *Mammography for Women with Disabilities": Training for the Mammography Technologist*. This self learning resource was designed by technologists themselves to assist them in providing quality mammography service to women with disabilities. The manual educates mammography technologists on the need to undertake outreach and breast health promotion to women with disabilities. It also outlines the barriers women encounter in the screening process and offers solutions to remove those barriers, includingdescribing adapted positioning techniques, use of supportive equipment and ideas on effective communication strategies.[67] The BHAWD website offers access to a number of BHAWD specific resources as well as links to relevant American breast cancer organizations.

Disaboom is an American website that offers information and resources for people with disabilities. The site offers a guide entitled: *Accessible Mammogram Screening for Women with Disabilities* which outlines some of the barriers women have experienced in attempting to access breast cancer screening as well as a step by step guide on how to "Get a Great Mammogram Screening".[68]

The Centre for Independent Living Toronto's website has a list of accessible breast screening clinics in the Greater Toronto Area.[5] It would be useful to identify and compile this type of information to be included in a national resource.

The Action des femmes handicapées de Montréal[6] "Access to breast Cancer screening programs for women with disability" project also developed a manual and video based on their report. [69]

The Public Health Agency of Canada developed a compendium of best and promising practices for projects under their; "Engaging Seldom or Never Screened Women in Cancer Screening" program. This report includes a number of resources that were developed across the country to increase access to breast cancer screening for women with disabilities. These were:

- Plain language documents, videos and workshops developed by Alberta Health Services and Grace Women's Outreach Programs to support women with intellectual disabilities to make decisions about their health care. [70]

- Online and plain language print resources developed by the Vocational and Rehabilitation Research Institute, Simply Health: The Breast – Health for Women project. [71]

- This document also outlined the recommendation to implement a 2009 review of the 2006 Consensus Guidelines for Primary Health Care for Adults with Developmental Disabilities to help increase awareness and screening rates for cancers including breast cancer.[72] Revised guidelines were to be published in 2010 which also includes a training program and information

[5] Please see Centre for Independent Living Toronto's website at http://cilt.operitel.net/Documents%20of%20the%20CILT%20Website/Accessible%20ones.pdf

[6] Please contact Action des femmes handicapées de Montréal for more information.
Phone (514) 861- 6903 or Email: admin@afhm.org

and tools to support the implementation process. Reaction to these resources from healthcare providers and families were positive.[73]

- An eight-week group-based curriculum entitled “Women be Healthy” for women with “mild to moderate” intellectual disabilities that includes informant on health, exposure to the medical setting and coping and assertiveness training.[74]

- The Female Sexuality Education Program developed by Surrey Place a community-based centre in Toronto, is an abuse prevention program for women with intellectual disabilities which includes how to do breast self exams and info on pelvic exams.[75]

Conclusion

The social determinants of health relevant to women with disabilities such as poverty, lack of access to education and employment, lack of accessible and affordable housing, congregate living arrangements resulting in high stress levels and inadequate income supports, put women with disabilites at a significant risk of poor health, acquiring serious health conditions and having limited access to health promotion activities.

There has been little attempt to conduct effective outreach and health promotion strategies that are specifically targeted to women with disabilities, therefore current health promotion resources and campaigns are largely ineffective for women with disabilities. Disability-sensitive cancer prevention resource tools, training workshops and educational materials are minimal as they pertain to women with disabilities. This is evident in the literature despite the growing knowledge that people with disabilities particularly women, experience higher rates of specific types of cancer as well as face considerable barriers to accessing health care and maintaining good health. It is also evident that women with disabilities are less likely than women without disabilities to receive pelvic and mammogram exams on a regular basis and are thus at a higher risk for delayed diagnosis and poorer prognoses and survival rates.

We also saw that health care personnel either do not feel equipped and knowledgeable on how to treat women with disabilities and/or have negative attitudes, assumptions and stereotypes that hinder their ability to provide quality care to women with disabilities. Given the feedback from women with disabilities and health care providers that were consulted, provincial/territorial cancer care programs do not appear to be providing adequate and accessible health care, nor a focused outreach to women with disabilities.

When women with disabilities were commisioned to design, deliver and reflect on research that was conducted, information was comprehensive, rich in detail and specific about the actions that needed to be taken. Ideas and recommendations for addressing this issue fell into the following five categories; 1) Creating an accessible physical environment including architectural, equipment and materials, 2) Developing accessible procedures and processes, 3) Developing and delivering women-centred, disability sensitive training for breast cancer screening health care personnel, 4) Designing and implementing effective outreach and health promotion strategies targeted to women with disabilities and 5) Advocating for specific organizational and broader level government policy reforms.

Enough information has been generated to begin informing and reforming breast health education, breast cancer screening and treatment. Future efforts therefore should be focused on knowledge translation and mobilization, i.e. taking the detailed feedback that women with disabilities who were consulted provided, and developing tools, resources and strategies to implement them in ways that will make concrete changes.

The review of the literature highlights the need to target different audiences and implement various types of strategies, i.e. accessible facts sheets that provide information on the breast screening process for women with disabilities, the provision of disability sensitivity training for health care workers, or lobbying for accessibility as a key part of the accreditation of health care facilities. The ultimate goal of all strategies should be universal access to health promotion efforts and the breast cancer screening process. Therefore a comprehensive strategy that operates on multiple levels is needed. On the individual level that would mean working with women directly to increase knowledge, raise awareness and develop self-advocacy skills. At the community level this would involve mobilizing, educating, and empowering the local community and community based health care supports around the inclusion of women with disabilities. Lastly on the broader policy level, a strategy would have to challenge and work

towards the reform of policies that would increase access for women with disabilities to proper breast health care.

The information, promising practices and minimal tools and resources that were identified in this environemental scan can be mobilized through a pan-Canadian community development strategy that would be rooted in local communities with the aim of both reaching women with disabilities and front-line workers directly and bringing these learnings to the provincial/territorial and national levels in a way that can influence policy makers. The most important building block of change is the recognition of lived experience and expertise, i.e. that those most affected lead the way in defining the issue and identifying solutions. As both the Montreal and Greater Toronto Area projects articulated:

> ".. we have forefronted disabled women's expertise about their own bodies and experiences". [76]

> "the voice of the individual living a specific situation is the best situated to identify and represent their reality at a given moment. [77]

With a few exceptions, the majority of work focused on women with mobility or physical disabilities. DAWN-RAFH Canada could not limit this review to physical disability given that we are an organization for all women with disabilities recognizing the importance of understanding the intersection of various experiences of marginalization (e.g. race, ethnicity, class, age, sexual identity, rural/northern, etc..) including the reality of multiple disabilities for many women. It is within this framework of inclusion for ALL women with disabilities that we would like to see work in the area of breast cancer screening proceed.

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