



# **What we know about Access to Cancer Screening for Women with disAbilities and Deaf Women**

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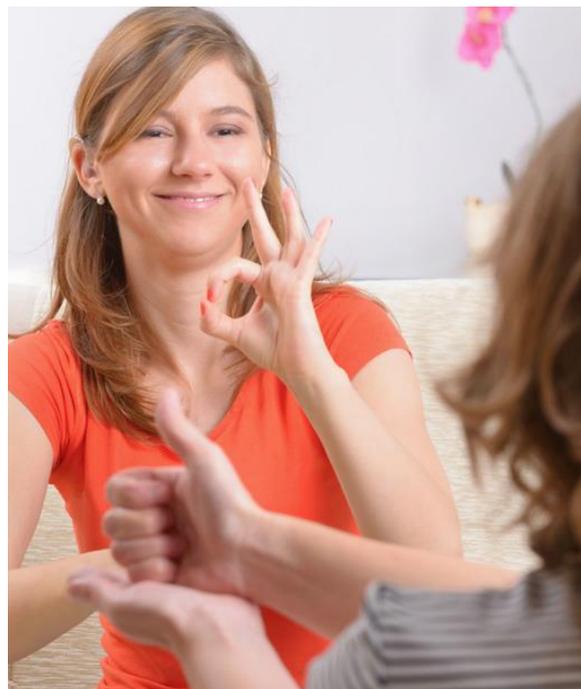


## What we know about women's experiences of disability and cancer

- Overall, women with disabilities and Deaf women are at a significant risk of poor health due to poverty, lack of access to education and employment, lack of accessible and affordable housing, congregated living arrangements resulting in high stress levels and inadequate income supports.
- 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.
- Women with disabilities and Deaf women face both systemic and physical barriers to cancer screening. These barriers are varied and maybe be related to agency policies and procedures that fail to address access issues for women with disabilities and Deaf women seeking services i.e. intake procedures that do not address accommodations of women prior to attending the appointment.
- Additionally barriers include mammogram machines that require standing or specific positioning; inaccessible exam tables; lack of access to information in ASL video format or qualified ASL interpreters for women who are Deaf, Deafened or Hard of Hearing; lack of communication supports for women who are non-verbal or spoken language interpreters for women whose second language is English or who are French speaking; lack of information about cancer screening in alternative accessible formats; and limited access to accessible/affordable transportation systems. As well, physical spaces may lack proper lighting and paths marked with textured strips for women who are blind or have vision loss.<sup>1</sup>



- Research undertaken during the development phase of “[Our Health Matters](#)”, a program that aims to increase access to health care services for people with disabilities and Deaf people, in particular cancer screening, found that most facilities did not have policies, procedures, or clear protocols for serving people with disabilities and Deaf people.
- Clinics working with people with disabilities often do not have enough time to provide appropriate accommodations (for example, extra time to explain the procedure or time to accommodate for mobility needs like transferring patients from wheelchairs to exam tables and not understanding that ‘adapted’ transportation systems run on different schedules which may conflict with the clinic appointment – often the person with the disability is blamed or expected to negotiate this issue.
- The most damaging barriers for women with disabilities are attitudinal barriers, which arise when health care personnel have negative attitudes, assumptions and stereotypes that hinder their ability to provide quality care to women with disabilities.
- As well, many health care providers tend to medicalize and/or pathologize disability; that is, they focus on the disability as the health problem rather than the overall health of the patient. As a result, women are less likely to participate in regular screening or are not encouraged to get screened because of these Health Care Professionals’ assumptions.
- 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.
- Currently, there is a lack of available disability-sensitive cancer prevention resource tools, training workshops and educational materials that pertain to women with disabilities and Deaf women.



## What is being done to improve access

- In order to promote equitable access to health for everyone, DAWN-RAFH Canada and our partners at the Canadian Association for Community Living (CACL) offer a program entitled [Our Health Matters](#). The program includes educational tools and training workshops aimed at improving the capacity of health care staff to provide more inclusive health care, along with sessions designed to enable people with disabilities and Deaf persons to increase their own awareness and self-advocacy.
- [Gateways to Cancer Screening](#), a community-based participatory project aimed at examining access for women with mobility disabilities, and composed of women's health researchers, disability advocates, and healthcare professionals have conducted studies to explore the experiences of women with mobility disabilities accessing cancer screening, as well as the perspectives of healthcare providers who work at a breast cancer screening centre. They learned that:

*"Women with disabilities live busy, fulfilling lives. They value their health and want to preserve their well-being. They want access to tests that will prolong their lives, and do a lot of work to arrange and attend cancer screening. Healthcare providers want to provide the best quality of care to women with disabilities*

*accessing cancer screening, but don't always know how to create an enabling environment in mammography."*<sup>1</sup>

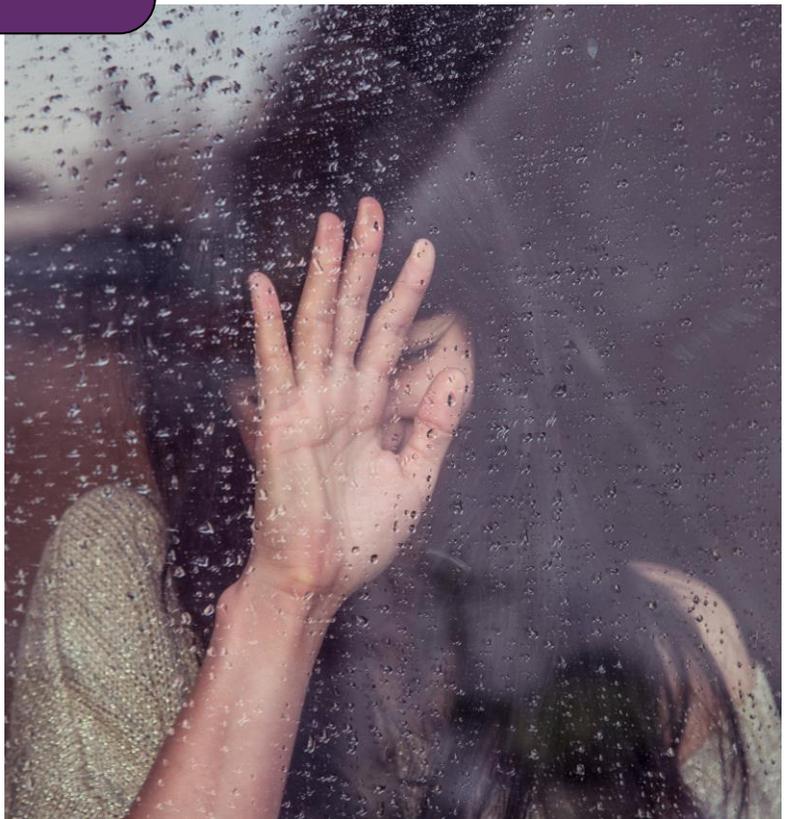
***Women with disabilities live busy, fulfilling lives. They value their health and want to preserve their well-being.***

- DAWN Canada has been building a strong body of resources related to women with disabilities and breast cancer, and also conducts an annual campaign to raise awareness of this

issue. DAWN Canada will be leading the development of a nationally accessible repository of articles, reports, resources and tools that deal specifically with the issue of women with disabilities and breast cancer screening. These tools will be available for use by health care providers as a guide to ensure they are addressing barriers for women with disabilities.

## Address systemic barriers (architectural, equipment and materials)

- Ensure accessible transit, parking, universal access, good signage, accessible washrooms, examination and waiting rooms, accessible mammography equipment and TTY telephones,
- Ensure consent forms can be understood by women with differing communication abilities
- Increase the number of facilities that have accessible exam tables, scales and screening technology and on-site attendant care



## Implement procedures and policies that improve accessibility

- Develop a good intake protocol for people with disabilities, which includes asking what kinds of supports/accommodations are needed while attending the appointment.
- Obtain more detailed information about the needs of the woman before she arrives for service, in order to be better prepared to serve her.
- Be aware that many women with disabilities and Deaf women have had previous experience with trauma (or are violence survivors). Providers need to be thoughtful in carrying out procedures in ways that does not re-victimize women.
- Refer clients to a clinic that has enhanced capacity for screening people with disabilities, if an individual's needs cannot be fully met. Call ahead to ensure appropriate referral.
- Allow for more time to provide appropriate accommodations (extra time to explain the procedure or time to accommodate for mobility needs like transferring patients from wheelchairs to exam tables). At time of intake, ask the woman when her para-transit return is so as to ensure that she does not miss her bus should the appointment be running late.



- Have portable attendant or personal support services available to support women with disabilities when they arrive at the appointment to help navigate the system, provide assistance with undressing/dressing, transferring onto the examination table or mammography chair, or washroom assistance if needed.
- Create safe and positive spaces for women with disabilities from the LGBT communities, immigrant and racialized, low income and of various age groups.
- Include breast screening as part of the annual/periodic medical exam.
- Provide training to increase awareness of Deaf culture and considerations for Deaf women coming to appointments i.e. booking ASL interpreters to attend the appointment.
- Provide training to staff members, that is specific to working with people with disabilities within the health care system.
- Get creative and explore opportunities to have Health Care Professionals working within the community to meet women with disabilities and Deaf women where they are.
- Contact and partner with disability advocacy organizations in your local community to provide advice and training.
- Increase communication with and between various health providers who refer patients so that staff members are aware in advance of the procedure what a person's needs are, and can be prepared with extra staff or time to appropriately accommodate each individual
- Prepare patients in advance of the examination about the procedure



## Conduct Accessible Health Promotion

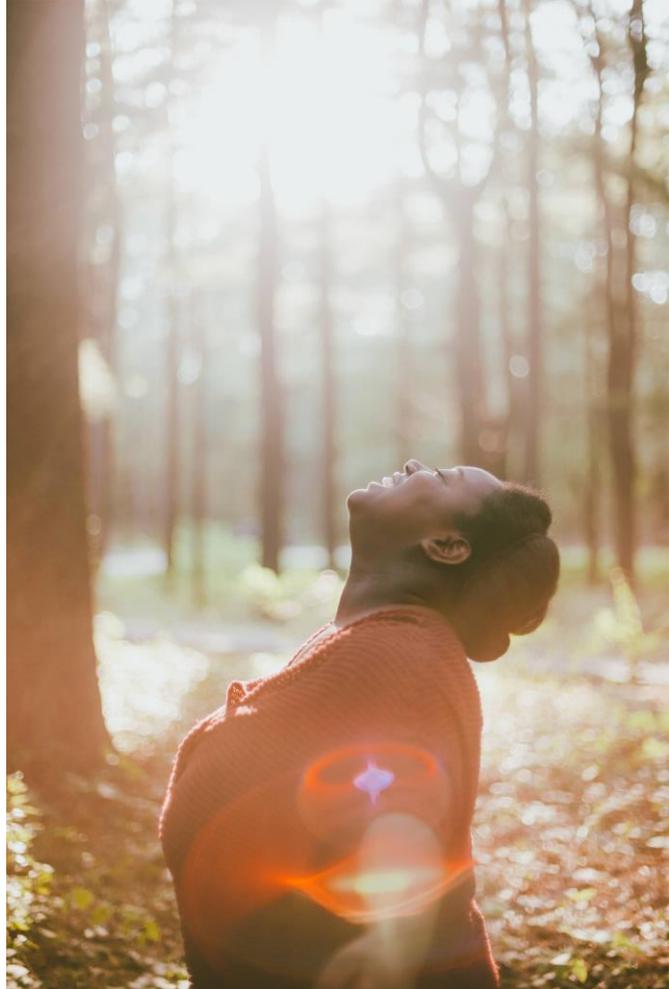
- Conduct on-site health education sessions for women with disabilities and Deaf women on screening guidelines, procedures and body-specific strategies;
- Ensure that educational outreach is specifically targeted to the disability and Deaf community
- Ensure that health promotion materials are written in clear language, and readily available and easily accessible to all people (eg. large print, Braille, audio, available on the internet, accessible by screen reader technology, in ASL and LSQ)
- Create materials that are visually reflective of women and people with disabilities
- Create DVDs that are captioned and in American Sign Language (ASL) and Langue des signes québécoise (LSQ), and that are linguistically and culturally appropriate for the diverse Deaf community
- Use qualified sign language interpreters and trained, qualified Audio Visual Language Interpreters (AVLIC's) who are knowledgeable about medical terminology to ensure interpretation is accurate for the Deaf client.
- At the discretion of the woman, allow for the presence of a family member or friend to assist with communication between the health care provider and the patient



## Encourage women to be their own advocates

Some ways in which women can advocate for themselves include:

- know that you can ask for a longer appointment
- ask if the clinic is accessible
- become knowledgeable of your own health issues and being attuned to your bodies
- find ways to avoid stress and prevent illness
- learn to access a variety of health and wellness information sources
- seek out facilities that could meet your disability needs
- seek out service providers who have expertise and sensitivity to your health needs



<sup>1</sup> Rajan, Doris. On behalf of DisAbleD Women's Network Canada (2012). *Environmental Scan on Women with Disabilities and Breast Cancer Screening. Identified Problems, Strategies, and Recommended Next Steps*. Canadian Breast Cancer Network.

<sup>11</sup> Devaney, Julie, Seto, Lisa, Barry, Nancy, Odette, Fran, Muraca, Linda, Fernando, Sharmini, Chandani, Samira and Angus, Jan (2009) "Navigating healthcare: Gateways to Cancer Screening", *Disability & Society*, 24:6,739 — 751

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