

DisAbled Women's Network
(DAWN) Canada



Réseau d'action des femmes
handicapées (RAFH) Canada

Executive Summary

Environmental Scan on Women with Disabilities & Breast Cancer Screening: Identified Problems, Strategies and Recommended Next Steps

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Background:

In 2009 the Canadian Breast Cancer Screening Initiative Underserved Populations (CBCSI) Working Group identified women in four sectors who typically do not receive adequate breast cancer screening: women with disabilities, newcomers and immigrants, First Nations, Inuit and Métis women, and geographically isolated women. It was determined that there was a need for policy guidelines, research and capacity building for both the women and relevant service providers. Consequently, the Canadian Breast Cancer Network contracted the DisAbled Women's Network / Réseau d'action de femmes handicapées (DAWN-RAFH Canada) to conduct a review of relevant projects, resources and literature related to the issue of access to breast cancer screening for women with disabilities.

Methodology:

An environmental scan of projects, reports, articles, and guides produced between 2002 and 2012 was conducted using major search engines, university databases, and through information gained from community-based experts who have an expertise in cancer, health and women with disabilities, particularly in the Canadian context. The findings are organized under two categories: 1) The Nature of the Problem and 2) Strategies, Promising Practices and Resources .

Key Findings: The Nature of the Problem

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

People with disabilities experience exceptional challenges to staying healthy and getting appropriate health care, for example adults with disabilities reported more than three times as many unmet health needs as the non-disabled population. More specifically;

- People with disabilities may be at greater risk of specific types of cancer, less likely to be screened and have poorer prognoses and survival rates
- With the move from institutional to community care for people with disabilities, mainstream health and social services have not been able to adapt to meet the needs of these populations. There are architectural barriers to health care, such as narrow doorways, inaccessible toilets and inaccessible examining tables, but attitudes represent the most damaging barriers

- Since people with disabilities have limited access to education and outreach efforts are inaccessible, health promotion resources and campaigns are often ineffective for them.
- Many girls and young women with disabilities have expressed 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”
- Another important barrier that was identified in accessing health care for girls and young women with disabilities was that parents may be overprotective, thus taking the lead in their child’s health care. This may lead to young women not getting the health care they need because they do not want their parents to know about a health condition.

Barriers to Breast Cancer Screening for Women with Disabilities

Breast cancer is one of the most prevalent cancers affecting women. Early detection through screening greatly improves survival rates, yet women with disabilities are not being screened. The result is a delay in diagnosis potentially leading to adverse outcomes.

The barriers for women with disabilities to access screening fall into five categories: 1) physical 2) communication 3) attitudinal and 4) economic. Examples of these include:

- 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.
- If women with disabilities do make it to screening facilities, they often unable to participate and health care providers tend to medicalize and/or pathologize them.
- The environment and the location of cancer screening facilities greatly influence effective access for women with disabilities.
- 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 experience the most difficulties in communicating with staff.

- Additional time may be needed to serve a woman with a disability, thus this can serve as a financial deterrent to health care providers to screen women with disabilities.
- The unreliability of accessible transportation systems was another key barrier to screening.

Key Findings: Promising practices

Promising practices identified through this environmental scan were grouped into five subcategories:

1) Creating an accessible physical environment including architectural, equipment and materials - There is a need to address physical and architectural limitations as well as adapting equipment and/or medical (e.g. mammographic) techniques and procedures. More specifically:

- ✓ Fund innovative technology to increase access.
- ✓ Need accessible transit, parking, universal access, good signage, accessible washrooms, examination and waiting rooms, accessible mammography equipment, TTY telephones, consent forms that can be understood by women with intellectual disabilities
- ✓ More places with accessible exam tables and screening technology and on-site attendant care that is clearly publicized to the disability community

2) Developing accessible procedures and processes - Examples of useful changes include:

- ✓ Have a point person who would support individuals in clinics, to navigate the system;
- ✓ Have a checklist/other tools for health care providers to ensure they address all the barriers for women with disabilities to access their service;
- ✓ Get staff out of medical facilities and into the community where women with disabilities frequent;
- ✓ Workplaces need education/awareness to accommodate cancer screening;
- ✓ Include breast screening as part of the annual/periodic medical exam.

- ✓ nationally accessible repository of articles, reports, resources and tools that deal specifically with the issue of women with disabilities and breast cancer screening;
- ✓ On-site health education sessions for women with disabilities on screening guidelines, procedures and body-specific strategies; and
- ✓ Create safe and positive spaces for women with disabilities from the LGBT communities, immigrant and racialized, low income and of various age groups.

3) Developing and delivering women-centred, disability sensitive training for breast cancer screening health care personnel - This is necessary in order to deliver more effective and positive breast cancer screening experiences for women with disabilities. Specific ideas include:

- ✓ Training should focus on attitudes for health care professionals right from the start of the screening process and debunked the myth that women with disabilities are not sexually active;
- ✓ Health care providers need increased sensitivity and knowledge about communicating with a range of women, including those with low-literacy levels, who may be non-verbal, have aphasia, or are non-English speaking or ESL/EAL; and
- ✓ Physicians need to look beyond the primary disability and explore other reasons for symptoms.

4) Designing and implementing effective outreach and health promotion strategies targeted to women with disabilities and Deaf women - Ideas include:

- ✓ Women with disabilities need education about symptoms and what questions to ask of their doctors;
- ✓ They need to be empowered and know how to care for their own health;
- ✓ Assist women on how to find accessible health care clinics/services throughout the province, especially outside metropolitan urban centres;
- ✓ Need accessible web-based information; and
- ✓ Strategic health messaging with disability-positive images and specific information for women with disabilities to support self-advocacy.

5) Advocating for specific organizational and broader level government policy reforms - Key policy recommendations identified in the research include:

- ✓ Access needs 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;
- ✓ Health care facility`s policies should include the provision of funding for accessible medical equipment and a process for phasing out old equipment and replacing it with new accessible models; and
- ✓ National guidelines/policies regarding cancer screening that include operational guidelines regarding access for women with disabilities for clinical staff, clinics and data collection are needed.

Conclusion

Future efforts to improve breast cancer screening for women with disabilities and Deaf women should aim for 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.