



We're Women, Too

Identifying Barriers to
Gynecologic and Breast Health Care
for Women with Disabilities

British Columbia
Centre of Excellence
for Women's Health

Vancouver, BC
CANADA

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Report available
in alternate formats



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Centre of Excellence
for Women's Health**

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Women's Health Reports

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Introduction

Many women face barriers to the health care services in their communities. Cultural differences, time, costs, childcare, knowledge deficits, language and literacy all play a role in how easy or difficult it may be for women to receive optimal health care (Thurston, 1996). The limited research that is available on the health needs of women with disabilities shows that these women face additional barriers in accessing health services (Becker, 1997). Many women with disabilities report that they receive health care only in the narrow area of their health that is directly impacted by their disability. By failing to see the whole person, health care providers neglect basic aspects of health and wellness.

The adverse consequences of accessing breast or cervical cancer screening too late or not at all are well documented (British Columbia Cancer Agency, 2000). Approximately 75% of women in British Columbia receive recommended cervical cancer screening (B.C. Cancer Agency, 2000), but how and when women with disabilities access cervical cancer screening in B.C. is unknown. The 1996/97 National Population Health Survey found that just 53.6% of eligible women in Canada had had a mammogram in the two years prior to the survey. However, in B.C. fewer than 50% of women who are eligible for screening mammography actually take advantage of this free service (B.C. Cancer Agency, 2001). The number of women with disabilities who do not receive mammograms is unknown. This lack of information impedes the development of policies and health planning for women with disabilities.

The purpose of the research study, “We’re Women, Too: Identifying Barriers to Gynecologic and Breast Health Care for Women with Disabilities,” was to address the following questions:

- To what extent do women with disabilities regularly

receive screening for breast and cervical cancer?

- What are the barriers that prevent women with disabilities from receiving this care?
- How can we use this information to improve screening?

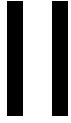
This study was conceived as community action research to be led by women with disabilities and to centre on women's experiences of living with a disability or disabilities. The research principles of the DisAbled Women's Network (DAWN) Canada were used to guide the research (Masuda, Appendix 1).

The study's advisory committee consisted of four people, three of whom identified as having a disability. The committee members represented nursing, medicine, research and advocacy work. One member, Shirley Masuda, was the primary researcher who helped guide the development of the research and carried out all of the interviews with the women.

Unfortunately, Shirley became ill through the course of the study and died before the work was analyzed and reported. It is Shirley who said "We're women, too," and it is in her honour, and in honour of the women who participated in this study and expressed the same message, that we chose the title of this report. Shirley's contribution was instrumental in keeping the work focused on the voices of women with disabilities. She is sorely missed.

The research was originally conceived to focus on the concerns of women with mobility disabilities. The women with disabilities who joined the research team, however, insisted on including women with all disabilities. They also guided our definition of disability and the classification of disabilities into categories. This is important because how a disability is defined impacts on attitudes and beliefs about women with disabilities and influences the interaction between those women and the health care system (Carty, 1998, p. 363).

Many women with disabilities report that they receive health care only in the narrow area of their health that is directly impacted by their disability.



Background

In Canada, and specifically in British Columbia, it is difficult to obtain accurate information about the overall demographics of disabilities and women with disabilities. In 1991 Statistics Canada conducted a Health Activity Limitation Survey (HALS) at the same time as the Canada Census. This national survey explored many aspects of the lives of people with disabilities, but did not include health. The HALS was not distributed consistently to institutions and, therefore, many thousands of Canadian women with disabilities in long-term care facilities and mental hospitals were not included in the data. In the HALS, roughly 15.5% of the population, or 4.2 million Canadians, reported some level of disability. The percentage in B.C. was slightly higher at 16.8%. These figures were not broken down by gender or detailed categories of disability. In 2001, following the Canada Census, the Participation and Activity Limitation Survey (PALS) surveyed people with disabilities living in households. The rate of disability for women aged 15 to 64 was 10.4% and, in women over 65, disability rates increased to 42% (Government of Canada, 2002, p.8). This study, like HALS, was not distributed to people living in institutions. PALS captured over a half a million fewer people than HALS did, which may partially account for the decrease in disability figures.

According to the PALS, “In Canada people are considered to have a disability if their condition restricts their ability to perform common activities such as working, going to school, traveling, walking, communicating or performing daily tasks at home” (Government of Canada, 2002, p.10) Most national and provincial organizations that represent people with disabilities have agreed on categorizing disabilities as either physical or mental. There remains, however, much disagreement on further subdivisions of the categories. We have chosen to use the categories identified by DAWN Canada. Those with mental disabilities have either:

- mental handicaps; or
- mental illness.

Those who have physical disabilities have:

- blindness or low vision;
- deafness or are hard of hearing;
- mobility disabilities;
- hidden disabilities (e.g., asthma, mild multiple sclerosis, allergies, heart conditions, etc.);
- learning disabilities.

Over the years there have been two other categories added to the list and they may each fall into both the mental and physical categories. These are:

- brain injuries;
- HIV/AIDS.

Information about the ability of Canadian women with disabilities to access primary health care services is scant. A recent survey (Veltman, 2001) of women with physical disabilities living in the metropolitan Toronto area evaluated the perceived extent of access to primary health care services and the level of satisfaction with the quality of these services. Of the 201 women in this convenience sample, 21.9% reported that their disability prevented them from receiving appropriate primary health care, while 38.3% reported difficulty accessing the equipment (examining table) in their family doctor's office. Results of the 1996/97 National Population Health Survey identified a

number of negative health and lifestyle characteristics (as well as higher age and Asia as place of birth) as significant predictors of never having had a mammogram (Maxwell, 2001).

Information about women with disabilities was not included in the report. Unless questions about the presence of disability are asked, it is difficult to ascertain whether or not having a disability is a risk factor for non-conformance with screening guidelines.

A recent United Kingdom study by Cheng and colleagues (2001) reported that non-ambulatory women with multiple sclerosis reported less cervical screening, mammography and breast exams than fully ambulatory or partially ambulatory women. The researchers speculated that lesser participation occurred because of failure to offer preventive services to women with disabilities, patient reluctance to participate, lack of equipment, and health provider reluctance to invest the additional time needed to accommodate women with disabilities. The researchers did not ask the women what their perceived barriers were.

Research from the United States provides more in-depth information. The National Study of Women with Physical Disabilities was conducted in 1994-1995 as a supplement to the National Health Interview Survey (National Center for Health Statistics, 1995). This study sought to determine the extent to which

women with disabilities regularly receive pelvic exams and mammograms, compared to women without disabilities. It also sought to identify the socioeconomic and disability factors that contribute to noncompliance and the reasons women with disabilities offer for not receiving regular cancer screening. The survey received results from 450 women with physical disabilities and 393 of their non-disabled friends, aged 18 to 65. Women with disabilities were significantly less likely to receive regular pelvic exams: 67.1% of those with disabilities compared to 72.8% of those without. Significant risk factors for non-compliance with screening guidelines included race and severity of functional limitations. Age, marital status, income, education level, and frequency of sexual intercourse were not significant risk factors. Among the 148 women who did not receive regular pelvic exams, the most frequently cited reasons were difficulty getting onto an exam table (37.2%), lack of time (31.1%) and inability to find a doctor who suits them (29.1%). No significant difference was found between women with and without disabilities, regardless of severity of functional limitation, in receiving mammograms.

In another study from the U.S., Gans (1993) and colleagues identified five commonly recognized reasons for inadequate health care services for people with disabilities: transportation problems, inaccessible offices, inadequate knowledge among health

care providers, provider attitudes, and inadequate insurance coverage. In two separate 1997 studies (Nosek; Becker), in-depth interviews were conducted with women with disabilities. Barriers to reproductive health care were identified that could be grouped into three categories: structural barriers related to access or physical accommodation, physicians' attitudes and lack of knowledge, and women's own knowledge of their health needs and their attitude toward the health care system.

A study reported by Chan and associates in 1999 examined Medicare patients and found that disability was a significant, independent risk factor for not receiving mammograms and Pap smears. This suggests that in Canada universal health coverage will not eliminate inequalities of access to mammograms and Pap smears for women with disabilities.

An extensive review of the medical literature from 1990 to the present was conducted; all studies in this subject area focused on women with purely physical disabilities. A British study looked at women with learning disabilities (Stein & Allen, 1999). Only 13% of the learning disabled women who were eligible for cervical cancer screening had a record of a Pap smear performed in the previous five years. This compared poorly with the remainder of the women in the district, 88% of whom had had Pap smears.

Factors that may have contributed to limited access for these women with disabilities are suggested by the authors, but no research was conducted to support their assumptions.

“We’re Women, Too: Identifying Barriers to Gynecologic and Breast Health Care for Women with Disabilities”, despite a self-selection process for a survey and the small size of the focus group, produced similar findings to the studies cited above.



Methodology

Surveys and a focus group were our methods of gathering information from women with disabilities, health care professionals and institutions.

A. Questionnaire Development

Three different questionnaires were used (Appendices 2, 3, & 4). A 19-question individual survey, a shorter institutional survey, and a health care professional survey were designed. The questionnaires and the questions for the focus group were designed by the advisory committee and reviewed with a group of women with disabilities for relevancy and ease of reading. Because the advisory committee recognized that some women, such as those with mental disabilities, might find it difficult to complete the questionnaire, women were offered the choice of answering the questions over the phone. A focus group was conducted that addressed women with disabilities' thoughts and feelings about gynecologic and breast health care.

B. Participant Recruitment

The questionnaire was mailed out (with a stamped, addressed, return envelope) to 742 women with disabilities in the Lower Mainland of British Columbia. Names and addresses were obtained from provincial disability organizations and Pacific DAWN. Forty-four questionnaires were returned due to distribution difficulties (moved (10), address unknown (32) and deceased (2)). Responses were received from 278 women (40% response rate).

A focus group was held to obtain qualitative information and add richness to the data. Recruitment was done through disability organizations (Appendix 6). Five women attended the group.

Physicians in Vancouver who were known to provide care for women with disabilities were identified and sent surveys (Appendix 3). Thirty-two surveys were mailed out; eleven were returned (34% response rate).

Institutions in British Columbia that were known to provide services and care for women with disabilities were surveyed for their understanding of the needs and services available for women with disabilities. Twelve institutions were identified, key people spoken to and sent surveys. Seven responded (58% response rate). Interestingly, the two institutions that are most identified with developmentally delayed individuals and mental illness did not fill in the survey and declined to have their residents participate in the research.

IV

Research Findings

A. Women with Disabilities Survey

Of the 278 completed questionnaires sent to women with disabilities, approximately 75% of respondents were between the ages of 31 and 60 years, 11% were between 18 and 30, and 14% were over the age of 65. Eighty women (29%) had been disabled since birth and another 29% had been disabled for 20 years or more. Respondents named 48 conditions causing disability, for a total of 359 identified disabilities. Eighty-one percent of the women classified their disability in a mobility category. The remaining 19% (53 respondents) were spread in small numbers across the other categories. The majority of women had multiple disabilities.

Age of Respondents

Age	Sample Size
18 - 30	32
31 - 45	114
45 - 60	92
60 +	40
TOTAL	278

Types of Disabilities of Respondents

Disability	# and %	Single Disability
Mobility	225/278 (80.9%)	13/225 (72.4%)
Hearing	17/278 (6.1%)	8/17 (47%)
Hidden	50/278 (18%)	10/50 (95.1%)
Visual	24/278 (8.6%)	2/24 (8.3%)
Mentally Handicapped	13/278 (4.7%)	2/13 (15.4%)
Learning	19/278 (6.8%)	3/19 (15.8%)
Mental Illness	17/278 (6.1%)	8/17 (47.1%)
HIV	0	0
Brain Injured	24/278 (8.6%)	4/24 (16.7%)

Aids Used by the Sample Population

The women were asked to identify what aids they used in the course of their daily living. In addition to the standard aids such as wheelchairs and canes, six women (2%) were respirator-dependent.

Cervical Cancer Screening

Thirty women (11%) indicated that they had never had a vaginal exam and Pap smear. A further 19 women (7%) were unsure if they had had this examination. One hundred and nineteen women (43%) had not had a Pap in at least two years, with 49 women (18%) noting that it had been more than five years since they had a gynecological examination.

For those who had had a Pap smear since they became disabled, their doctor's office was the most likely place for them to have this test, followed by the hospital. Interestingly, five women identified their home as the place where they had their gynecological examinations.

Reasons Why Women Hadn't Had a Vaginal Examination in the Last 5 Years

Reason	#	% of sample n=278
No one suggested it was needed.	17	6%
No accessible examination table at GP's office.	14	5%
Doctor states that it was not necessary.	6	2.1%
Not sexually active.	6	2.1%
Assumed it was impossible due to disability.	4	1.4%
Too young and not sexually active.	3	1.0%
Already has lots of appointments.	3	1.0%
Memory problems.	1	0.3%

The majority of women (89%) thought it was important for women with disabilities to have regular vaginal examinations, for the following reasons:

To monitor and prevent disease.	141	57%
Just as important for disabled women as for any women.	95	38%
Cannot feel if something is wrong, if a muscle tone changes.	7	3%
Because we sit more than non-disabled women do.	2	1%
We have weaker immune systems.	1	0.3%
If you are sexually active.	1	0.3%

A few women (n=7) answered “No” to the question of whether gynecological exams are important. Their reasons were as follows

Just do not think it is necessary.	3
It is too invasive.	1
Doctor states that it is not necessary.	1
Do not care about it.	1
Cannot because of catheter.	1

The women were asked if they needed a wheelchair-accessible examination table. Not surprisingly, 48.5% of the women (n=208) who identified as having a mobility disability indicated the need for this table.

Breast Examinations

Thirty percent of the respondents had not had a breast examination for at least five years and twelve percent indicated they had never had a breast exam. Of those who did have breast examinations, the doctor’s office was the usual place.

Place of Examination	# of women
Doctor's office	91
Hospital	18
Home	17
Mammography clinic	20
Cancer clinic	2
Arthritis centre	2

Only a few of the respondents who had not had a breast examination gave reasons related to disability:

Reasons for Not Having Had a Breast Examination	# of Women
Does self-exams, no need for someone else to do as well	18
Doctor has never suggested that it was needed	18
Too young	7
No access to mammography that accommodates w/c	7
No accessible table at doctor's office	3
Have not found any lumps on self-exam	2
Uncomfortable with doctor	2
Disabled all her life so feels does not need exam	2
Breasts too small	2

However, the vast majority of women (267 or 96%) clearly thought it was important for women with disabilities to have regular breast examinations, and gave these reasons:

To monitor for abnormalities, especially cancer	125
For the same reasons as any woman, disabled or not	108

The last few questions asked respondents about accessible facilities for vaginal or breast examinations. Most of the women, (231, 83%), did not know of any place with accessible facilities for

A large majority of respondents felt that an accessible centre for breast and vaginal examinations should be established.

these exams. However, 36 respondents reported they did know of an accessible facility, but most were unsure if women with disabilities used it.

Not surprisingly, a large majority of respondents felt that an accessible centre for breast and vaginal examinations should be established: 232 (83%) answered “Yes” to this question.

B. Focus Group

The focus group, despite being very small (five women), added richness and detail to the data. The women who participated agreed to be tape-recorded and the discussion was transcribed.

For the women in the focus group, gynecological health meant getting Pap smears on a regular basis. When asked whether they felt their gynecological health needs were being met, a mixed response was received. Two women were receiving what they noted to be wonderful care, although they recognized the uniqueness of their situations. For example, “I didn’t go to a doctor for a long time because most examining tables were completely inaccessible. But now I have this wonderful woman GP and she did a house call and she came with a little light that she wore strapped to her head.

She used this while she did the Pap test.” Other women, however, were not as fortunate. As one woman said, “Even though I had had cervical cancer, there were years where I didn’t get Pap smears on a regular basis because I didn’t have a doctor that understood me as a person ... so I just didn’t go see anyone.”

Breast Health Care

In response to questions about the meaning of breast health care, the women focused on the things that hindered either mammograms or breast self-examination (BSE). One woman described the difficulty of doing breast self-examination, “If you can’t feel, or if your hands don’t work correctly, then it’s kind of a challenge. You might get bumps but you won’t be able to feel them.” Another woman stated simply that mammograms “are inaccessible to someone who sits down all the time ... The machine is not built for sitting down.” Others described their mammogram experience as awkward, especially in terms of the actual procedure.

The women who participated in the focus group described a number of impediments and supports for gynecological and breast health care. These can be divided into four

categories: safety, accessibility, the importance of physicians, information deficiencies, and attitudes. Although there is much overlap between the areas, separating them allows for a more focused look at the various issues.

Safety

Childhood sexual abuse and/or abuse at the hands of a health care professional were seen as impediments for women with disabilities seeking out gynecologic and breast health care. One of the women described how childhood sexual and physical abuse continued to influence her health care encounters. She recounted the lack of awareness on the part of health care professionals in dealing with survivors of abuse:

“[Women with disabilities] have issues around their breasts and reproductive areas ... that’s what’s been traumatized.” Other women added, “If someone has been assaulted, then it becomes a whole issue of safety,” and “I was in a trauma survivor group for a while and I knew women who were abused by medical professionals so they didn’t even feel safe coming to a hospital.” “I know survivors who didn’t go for good medical care because they didn’t know where to go, they didn’t know who was a safe doctor.”

The theme of violence against women was apparent throughout the focus group, with all women contributing observations. “A lot of survivors [of sexual abuse] just avoid dealing with

their gynecological health ... so it becomes a non-issue to the medical system,” said a woman with paraplegia.

Accessibility

Being able, or unable, to get up on an exam table or into the correct position for the mammography machine were raised as key issues. Women who have extensive mobility disabilities are clearly unable to use these machines. However, accessibility to care is a much broader issue than problems with machinery. “With a lot of disabilities,” one woman with quadriplegia pointed out, “it’s not just getting up and down, it’s hard getting on the table, having someone help keep the area exposed. If you can’t do your own dressing and undressing, who’s going to do it? Who’s going to help you?” Her experience was mirrored by another participant, who also has a mobility disability: “You might be able to get in the building and if you can ... you might not be able to get on the bed.” Space, in terms of how big a provider’s office is, becomes problematic when extra people and equipment are needed: “My doctor’s office is pretty small and it wouldn’t fit someone in a wheelchair and two other people.”

A woman’s ability to access services also depends on the nature of her disability. A woman with mobility concerns may need an accessible table, but a woman who is deaf or hearing impaired may require a signer, and a

“I went through a lot of GP’s before I found someone with the patience to show me how to do BSE.”

woman with a mental illness may require the attendance of an outreach worker, and so on. One woman with manic-depressive illness explained her reason for avoiding Pap tests, “The doctor wouldn’t understand me, then I would lose my temper, then the doctor wouldn’t want to see me because ... thought I was crazy ... they couldn’t deal with it.” Another woman speculated, “Imagine being blind and having your first internal ... especially if it’s not done sensitively with someone explaining it to you.” Essentially, the women in the focus group explained that the nature of the disability is a major determinant in access to services.

How long a woman has had a disability or where she is in the trajectory of a progressive illness is a third determinant. As a woman with a spinal cord injury explained, “There’s so much to absorb after you’ve had a spinal cord injury, breast examinations are low on the list of priorities.” Another woman added, “Say you are a young woman and you break your neck. You have an awful lot of things to worry about, but it would never occur to you to worry about whether your hands feel anything or your breasts tell you anything.”

The lack of somatic ability also affects the decision to seek access to services, as a woman with paraplegia who also

had a history of cervical cancer noted. “I couldn’t feel anything and I was just afraid to go.”

Importance of the Physician

The women in the focus group had encountered health care providers who ranged from very caring and creative professionals, such as the physician who provided cervical screening in the woman’s own home, to insensitive caregivers. For some women, even locating a physician was problematic. “Women with developmental disabilities ... even just finding a doctor who would deal with them was a big issue.”

Participants remarked that the physician needed to be very knowledgeable and comfortable about both screening for cervical and breast cancer and the woman’s particular disability. For example, one woman, who is a quadriplegic, talked about learning how to do BSE, “I’m lucky that I ran into this doctor at the university who grabbed my arm and showed me what to do.” Another said, “I went through a lot of GP’s before I found someone with the patience to show me how to do BSE.”

Interestingly, two of the women credited their good experiences with physicians to “good luck.” This was countered with a poignant comment from another

participant, “It shouldn’t be luck of the draw. It shouldn’t be hit or miss. That’s not a healthy way to deal with women’s health issues.”

Information and Attitudes about Screening

Attitudes toward breast and cervical cancer screening, on the part of the health professional and the woman with the disability, impacted on whether or not women had Pap screening. “I think for people who are coping with many difficult issues, that’s not a priority, unless someone draws it to your attention.” The woman in the focus group who had a mental illness remarked that “dealing with a GP who didn’t understand their disability” was a barrier to accessing any health care and that “Doctors need to be educated about accessibility and about the different disabilities.”

Attitudes of health providers are reflected in whether or not screening services are made accessible. “Most people, if they aren’t in a wheelchair and haven’t been around people in wheelchairs, just don’t think about it,” one woman commented.

The women with disabilities also acknowledged that both women and their health care providers needed to take an active interest in pursuing and offering accessible screening services. Much of the information about screening services for women with disabilities isn’t readily available in accessible formats. “It’s certainly not available in alternate formats. It doesn’t deal with women who are blind, who are deaf, women who have learning disabilities who aren’t able to understand. It’s not that available to women with mental health issues.”

There was also general agreement that some of the responsibility for lack of knowledge and participation in screening belonged to the individual woman with a disability. One woman said, “There are three steps before coming to the clinic that have to do with education, knowledge and an understanding that they should show up and take advantage of the facilities.” This, however, was countered by one participant who is involved in advocacy work: “If you are talking about women who are disabled, you’re talking about women who’ve gone through a totally different socialization process than you or I have. Women who don’t have the

“It shouldn’t be luck of the draw. It shouldn’t be hit or miss. That’s not a healthy way to deal with women’s health issues.”

confidence to do the kind of things we're talking about, to seek out information. Women who don't even know that they have the right to do that. Never mind that they, by luck, get the right kind of medical people in their lives."

C. Recommendations from the Focus Group

The women in the focus group were able to offer concrete suggestions in four specific areas to improve cervical cancer and breast cancer screening in the women with disabilities community: training, protocols, physical access and information.

Training

- Ensure staff are trained in sexual abuse trauma.
- Ensure staff are trained about mental illnesses.
- Ensure staff are trained in disability issues.
- Train medical students in disability issues.

Protocols

- Provide an all-women environment.
- Allow any health care provider to book the accessible room/table.
- Establish a central place for specialized screening services.
- Be open to alternative positions for examinations (i.e., side lying

for pelvic exam).

- Offer house calls if necessary.
- Be open to improvisation, which is a necessary part of being disabled.

Physical Access

- Provide an accessible table.
- Provide space big enough for the person, her doctor and her personal attendant.
- Improve accessibility by working with the disabled community.

Information

- Encourage screening through the mental health services.
- Provide multi-format pamphlets and information.
- Provide information specific to women in wheelchairs.
- Spread knowledge about patient rights to health services.
- Provide aid on how to navigate the health care system.
- Encourage disability groups to educate the people around them. Let people know when a problem exists.
- Target specific groups (i.e., work with the Canadian National Institute for the Blind to develop a pamphlet in Braille, set aside a time for blind women to use the facility).
- Let everyone know the service exists.

D. Physician Survey

Eleven surveys were returned by physicians who had been named as “disabled friendly” by women with disabilities affiliated with The Disability Health Action Group. These physicians reported that they provided regular health care for 107 women who they identified as having a disability. Just over 80% of the physicians reported that they provided care always, or almost always, in their office, while only one reported providing most care in the woman’s home. However, five reported that they did sometimes visit the woman’s home to provide health care services. Eight of the eleven physicians provided Pap smears for all or most of their women patients, and three for only some patients. Interestingly, two physicians stated that they did not provide gynecologic care for patients who they felt were too intellectually impaired to understand the nature of the exam and so might experience the exam as traumatic. The responses for breast health care showed that all 11 physicians performed breast exams on all or most women with disabilities, and 10 referred all or most for mammograms.

E. Institutional Survey

Seven surveys were completed by administrators or health care professionals employed by institutions/ organizations that provide services and care for women with disabilities. All but

one of the organizations exclusively provides health services, with the exception being an advocacy organization for people with paraplegia. As an advocacy group, its role is to provide expertise on issues related to people with disabilities and advise programs on how to meet the needs of that population. All of the organizations have a provincial mandate (See Appendix 6 for a list of the organizations). Five of the seven organizations serve only women clients. The rehabilitation hospital noted that 50% of their population is female and the advocacy organization noted that about 2,000 of their 6,000 clients are female.

All of the organizations have health programs designed to meet the health needs of their clients. Five noted they have programs designed exclusively for women, irrespective of disability. These programs include:

- programs promoting continence (fecal and urinary);
- gynecology clinic;
- cervical screening;
- mammography; and
- maternity services.

In addition, the advocacy organization provides counselling services for women and their families about living with paraplegia.

Fifty percent of those surveyed did not think their services were well utilized by

women with disabilities. Two others noted that there was no way of knowing if women with disabilities used the services because program data are aggregated across the province and not identified by disability. The Cervical Screening Program of the Cancer Agency was the only health organization that indicated that women with disabilities had made the organization aware of their specific health care needs.

Five of the seven organizations provided examples of specific health care needs of women with disabilities:

- Accessible care and accessible facilities in which women who are wheelchair users can obtain tests and appropriate medical examination. (Paraplegia association.)
- Mammography machinery that is accessible from a wheelchair, especially for women with higher quadriplegia or who are severely disabled. (Mammography program.)
- A double-appointment in order to provide a longer time for physically or mentally challenged women. (Mammography program.)

V

Discussion

The initial aim of this study was to examine women with physical disabilities in the Lower Mainland to see if their experiences were similar to those of physically disabled women described in other studies. By including qualitative questions, we sought to gain an understanding of the causes of their limited access to gynecologic and breast health care services. However, this focus was changed significantly by the women with disabilities who joined the research team and insisted on including women with all disabilities in our research group. The broadened research focus prevented us from reaching statistically significant conclusions regarding the barriers these different groups face. Nevertheless, it did enable us to introduce and discover many different and significant research questions.

We found that women in our limited convenience sample received regular cervical and breast cancer screening less frequently than the general population (ranging from 52-70%) in their region. While the lowest rates for cervical cancer screening occurred among women who required a wheelchair accessible table, those with a brain injury, mental handicap, or visual disability were also less likely than the general population to receive these exams. A high percentage of those with mental health and mobility disabilities had a single disability, but those in the other disability groups were more likely to have multiple disabilities. This fact, and the small number of respondents in many of the categories, makes it difficult to identify significant reasons for poor access.

The qualitative portion of the study provided insight into barriers other than physical ones that limit access to health maintenance care. Our data regarding the impact of past sexual abuse on this group of women deserves further investigation. Many excellent suggestions for program development also came from this group.

For women in this study, the ideal of universal access to care was compromised by physical and psychosocial obstacles.

The literature on the gynecologic and breast health needs of women with disabilities suggests that this population – particularly those with more severe functional impairments – does not have the same level of access to care as the non-disabled population. This is despite the fact that women with disabilities are equally at risk – if not more so – for breast and cervical cancers as their non-disabled counterparts. In her talk to the Breast Health Access for Women with Disabilities meeting in 1999, Dr. Wanda Jones pointed out that common sense – not data – tells us that some women with disabilities might be at increased risk for breast cancer. Reasons for the increased risk include more frequent x-rays, differences in exercise and nutrition, prolonged use of certain medications and late childbearing or nulliparity. These lifestyle differences create a sense of urgency for care providers to ensure universal access to mammography and cervical cancer screening.

For women in this study, the ideal of universal access to care was compromised by physical and psychosocial obstacles that demand resolution if the population of women with disabilities is to receive adequate care. Although we found that a high number of respondents thought it was important for women with disabilities to

have regular vaginal exams, 50% had not had screening in the last 30 months, a significantly lower rate than the rate for their non-disabled counterparts. Several issues contributed to this low rate, such as the lack of an accessible examination table in physicians' offices. Similarly, the need for regular mammography screening was seen as important by participants in the study and again, reasons for non-compliance included the inability of the present screening technology to accommodate women in wheelchairs and the lack of accessible tables in doctors' offices for manual exams.

A range of disabilities was reported by women in this study (Appendix 7), pointing to the need for a range of services. As one respondent commented, "Some people can get by with considerably less, some people need [more]. We have to be able to service the whole community." To accomplish this, the physical space offered must be big enough to accommodate a person in a wheelchair and her companion, if she chooses to bring someone along for assistance, as well as the physician. Service of this nature also requires advocates or outreach workers to support women with developmental disabilities or women who have experienced sexual trauma to receive sensitive care. Clearly, women

with disabilities are not a homogeneous group: this gives rise to the need for information, flexibility and responsiveness to the needs of individual women.

Psycho-social challenges to accessing care include a lack of awareness on the part of women that screening exams were important, respondents' physicians telling them it wasn't necessary, and respondents' own assumptions that such exams were impossible due to their disability. These challenges were not limited to conceptual challenges but included finding physicians who were sensitive, patient and informed about a particular disability or disabilities in general. At their point of access to care, physicians play a crucial role. As one respondent noted, "I was really fortunate to see a wonderful doctor [with] a wonderful approach. I think, had I met somebody else who wasn't as comfortable dealing with women's gynecological issues, it might have been harder dealing with it."

Most of the women in the focus group reported having positive relationships with physicians, but they stipulated this was only after they had made a concerted effort to find a sensitive physician. However, even when

appropriate care was found, open communication between patients and their caregivers was not always forthcoming. As one respondent noted, "It is embarrassing to admit to your GP that you're not doing [breast exams], because you're supposed to be doing it." For women in this study, the consequences of not finding practitioners sensitive to the nuances and implications of women's disabilities included non-treatment.

The key role physicians play in creating an accessible space for women calls for support and training for all physicians so that finding appropriate care is not "the luck of the draw" for women with disabilities. One respondent noted the valuable role her physician plays in training medical students: "I have a GP who trains medical students and he's got an incredible amount of patience. I think we need to get to the medical students and let them know about the issues and help them understand disabilities." Proactive involvement of members of the medical community – such as the one described above – is crucial in raising awareness among physicians.

There is a high rate of physical and sexual abuse among women who are

"I think we need to get to the medical students and let them know about the issues and help them understand disabilities."

disabled. Regardless of age, race, ethnicity, sexual orientation, women with disabilities are assaulted, raped and abused at a rate two times higher than the general population (Cusitar, 1994). This means that about 83% of women with disabilities will experience violence in their lifetime (Sobsey, 1988). And, the more disabling the condition, the more likely a woman is to be assaulted. Much of this abuse is at the hands of family members or caregivers (who include physicians, nurses, therapists and personal care attendants).

Underlying the discussion of access, therefore, is the need for a safe environment. When a sense of safety is not forthcoming, the consequences involve avoidance of care. This contributes to the underrepresentation of the needs of survivors of sexual abuse in gynecological and breast health care. As one focus group participant said, “A lot of survivors just avoid dealing with their gynecological health. So it becomes a non-issue to the medical system.”

As with their non-disabled counterparts, a woman with a disability’s gynecological and breast health care occurs within the context of her life. For women in this study, this context included physical or mental disabilities that often took precedence over less urgent, preventative health care needs. The contextualization of gynecological and breast health care for survivors of sexual abuse is even more complex due

to the interplay of past traumas – sometimes at the hands of medical professionals – and the need to find a sympathetic practitioner. One participant noted, “I know survivors who didn’t go for good medical care because they didn’t know where to go, or didn’t know who was a safe doctor. They’re dealing with so many other issues that they might not realize the importance of breast self-examination.” For the women in this study, this intricate context draws attention to the complex relationship between disabilities and health care.

The women in this study described the importance of self-advocacy, at the same time recognizing that some women with disabilities may not have the resources or awareness to advocate for themselves. One participant in the focus group said, “I think the onus is on individuals to educate themselves, to seek help. There are education and information resources available. The onus is on the individuals in the non-disabled community to self-educate ... the onus is on the disabled community as well.” The notion of advocacy also extended to educating others about disabilities. One focus group participant noted, “It’s up to people [with disabilities], whether they have MS or whatever, to educate the people around them.... Most people, if they aren’t in a wheelchair and haven’t been around people in wheelchairs, just don’t think about it.”

The expectation of advocacy, however,

may also lead to the perpetuation of existing inequalities. As one participant said, “If you leave it for people to figure out for themselves then that’s what will happen. Some will figure it out and some won’t.” This sense of responsibility extended to educating the medical community about one’s disability and how it affects one’s gynecological and breast health care needs. “I think what we are talking about has to do with the medical people’s attitude and their education about what’s possible ... I’m sure they don’t get taught those kinds of things.”

The need for self-responsibility that underlies many of the comments in the focus group, points to the need for a mechanism to facilitate self-responsibility. It also raises the issue of the accessibility of information. The lack of alternative formats to convey information was noted as a limitation, excluding women who are blind, deaf, or dealing with learning disabilities. Several participants suggested the development of informational pamphlets targeted at specific populations.

Research Limitations

Due to the diversity of women with disabilities, data from this study cannot be generalized to represent all women with disabilities. Self-selecting sampling also limits the inclusiveness of the data. Physicians were contacted through word-of-mouth referral, which limits the applicability of their responses to other

physicians. The institutional survey was limited to organizations in the Lower Mainland of British Columbia.

VI

Conclusion

The results of our study suggest general agreement with more extensive studies. Our research suggests that further investigation is needed into the specific barriers that women with non-mobility disabilities face. We also wish to emphasize the necessity of involving women with disabilities in the research group. Their personal perspective enriched both the research data and the experience of the researchers.

Clearly, the presence of a disability (or disabilities) does not negate the need for gynecologic and breast health care. Programs and materials are needed that inform women about how disability can affect their reproductive and breast health, and how they can work with health care providers to ensure that they are receiving the same quality of service as women who do not have disabilities. The participants in this study clearly articulate a list of ways this can be achieved. Responses from physicians who provide care to women with disabilities also suggest ways in which the needs of the population can be met. This information, along with the clear articulation of obstacles to care by women with disabilities in Vancouver, is a call for action. This call has been answered through the development of a gynecologic screening program and facilitation of breast screening for women with disabilities at Children's and Women's Health Centre of British Columbia, which opened in April 2002. Data from this study, along with the continuing encouragement of the disabled community, has contributed to creating a space that meets the health needs of women with disabilities.

The Access Clinic

The Access Clinic at Children's and Women's Health Centre of British Columbia provides breast and cervical cancer screening for women with disabilities who are not able to have a Pap or clinical breast exam in their doctor's office. The clinic was

planned with the help of an advisory group, which consisted of a number of women with disabilities and health care professionals and administrators. The clinic's mandate is to help women with all types of disabilities have these simple tests carried out in a safe and respectful way. For more information please call B.C. Women's Health Centre (604-875-3060) and ask for the Access Clinic.

“I’m a person with a disability. I have a disabling condition that affects certain areas of my life. But it doesn’t affect others. I think that it helps me to keep that in mind. I think it helps to educate people that we’re women and we have women’s issues ... whatever our backgrounds ... we all have the same issue of reproductive health. It has to be dealt with.”

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Appendix 1

DAWN Canada Research Guidelines

DAWN Canada has been observing and distributing the following research guidelines since 1995. Shirley Masuda first drafted them during her work on “Don’t Tell Me To Take a Hot Bath: Resource Manual for Crisis Workers” (1995).

1. The need for research is determined by the disabled women’s community.
2. Research must always benefit women with disabilities.
3. Research must be done by members of the disabled women’s community because members:
 - a) know the issues and priorities of the community;
 - b) understand the day-to-day reality of women who are disabled;
 - c) understand the political and social interactions (dynamics) of the community; and
 - d) can examine (analyze) data within the framework of these dynamics.
4. Research actions resulting from the research must be directed toward making positive change for women with disabilities.
5. Research participants will be given the results of the research.

Appendix 2

Gynecologic and Breast Health Needs of Women With Disabilities

SURVEY FOR INDIVIDUALS

The British Columbia Centre of Excellence for Women's Health has undertaken this survey to determine the needs of women with disabilities for accessible gynecologic (vaginal/internal) and breast health care. If you are a woman with a disability we would appreciate your completing this questionnaire and returning it in the addressed, stamped envelope. Completing this questionnaire implies your consent to participate in this survey. If you do not want to participate in this survey do not complete the questionnaire. Thank you for your help. **Please return by October 29th.**

What City/Town do you live in? _____

1. How old are you?

- 18-30 31-45 46-60 over 60

2. What is/are your disability or disabilities?

3. How do you classify your disability?

- | | |
|---|--|
| <input type="checkbox"/> Mobility | <input type="checkbox"/> Learning Disabled |
| <input type="checkbox"/> Hearing | <input type="checkbox"/> Mental Health |
| <input type="checkbox"/> Hidden | <input type="checkbox"/> Brain Health |
| <input type="checkbox"/> Visual | <input type="checkbox"/> HIV/AIDS |
| <input type="checkbox"/> Labeled Mentally Handicapped | |

4. Do you use any of the following aids?

- | | |
|---|--------------------------------------|
| <input type="checkbox"/> Wheelchair/scooter | <input type="checkbox"/> Walker |
| <input type="checkbox"/> Crutches | <input type="checkbox"/> White Cane |
| <input type="checkbox"/> Cane | <input type="checkbox"/> Hearing Aid |

Other (Please specify) _____

5. How long have you had a disability? _____

6. When was your last vaginal examination and PAP smear done? _____

7. Do you need a wheelchair accessible examination table in order to have a vaginal and breast examination?

Yes No

8. Have you had a vaginal examination and PAP smear done since you became disabled?

Yes No

If yes, When? _____

If yes, Where? _____

9. If you have not had a vaginal examination since you became disabled why not?

10. Do you think that it is important for women with disabilities to have regular vaginal examinations?

Yes No

If yes, why? _____

If no, why not? _____

11. When was your last breast examination done? _____

12. Have you had a breast examination done since you became disabled?

Yes No

If yes, when? _____

If yes, where? _____

13. If you have not had a breast examination since you became disabled why not?

14. Do you think that it is important for women with disabilities to have regular breast examinations?

Yes No

If yes, why? _____

If no, why not? _____

15. Do you know of any place where women with disabilities who need an accessible examination table can have regular vaginal and breast examinations?

Yes No

If yes, where are these services located? _____

16. Do women with disabilities use these services?

Yes No Not Sure

If no, why not? _____

17. Do you think a centre should be established that offers accessible vaginal and breast examinations to women with disabilities?

Yes No Don't Care

18. Would you come to a program for your vaginal and breast examinations?

Yes No

If no, why not? _____

19. What would you need to make the services accessible to you?

Please phone 1-800-875-2258 and leave a message:

- If you want more information about this project
- If you want to complete this questionnaire by phone
- If you live in the Vancouver area and are willing to participate in a focus discussion group
- If you know other women who would be willing to complete this questionnaire.

Appendix 3

Gynecologic and Breast Health Needs of Women With Disabilities

SURVEY FOR PRIMARY CARE PROVIDERS

1. Please estimate the number of non-geriatric patients in your practice who have disabilities:

Number of men: _____ Number of Women: _____

2. Indicate where you visit your patients:

	Always	Almost Always	Some-times	Rarely	Never
My Office Only					
In Patient's Home					
Patient's Home Only					
Combination of My Office And Patient's Home					
Other (Please Sepcify)					

3. How many of your women patients, who have disabilities, do you perform routine Pap Smears and pelvic exams for?

all most some a few none

Approximately what percentage of your women patients with disabilities do not receive gynecologic exams from you? _____

4. For those who do not receive this care from you, please indicate the reason(s) and if possible the number women it applies to:

A pelvic exam is not indicated for this patient

Number of women it applies to _____

I do not have access to an exam table to which my patients are able to independently transfer

Number of women it applies to _____

My patients receive their gynecologic exams elsewhere (please state where)

Number of women it applies to _____

Other reasons why you do not provide gynecologic exams (Please specify)

Number of women it applies to _____

5. How many of your women patients who have disabilities, do you perform annual breast exams for?
- all most some a few none

6. For those who do not receive breast exams from you, please indicate the reasons why and, if possible, the number of women it applies to.

I believe these exams are not indicated

Number of women it applies to _____

I do not have access to an exam table that can be adjusted to my patients' physical limitations and allow adequate exams

Number of women it applies to _____

I do not have access to an exam table that my patients can transfer to independently

Number of women it applies to _____

My patients receive this care elsewhere

Number of women it applies to _____

Please describe where the women get breast exams.

Please list any other reasons why you do not perform annual breast exams for your women patients.

7. How many of your patients receive screening mammograms when indicated?

all Number of women it applies to _____

most Number of women it applies to _____

some Number of women it applies to _____

a few Number of women it applies to _____

none Number of women it applies to _____

8. Please indicate reasons why your patients would not have mammograms.

9. Are you aware of any resources and facilities in the community specifically designed to meet the health needs of your women patients who have disabilities?

Yes No

If yes, please describe these services.

Appendix 4

Please enclose with this questionnaire information about your institution.

Gynecologic and Breast Health Needs of Women With Disabilities

SURVEY FOR COMMUNITY ORGANIZATIONS

Name of your organization _____

Name of person completing this questionnaire _____

Position of person completing this questionnaire _____

1. How many clients does your organization serve or represent? _____

Of this number, approximately how many are women? _____

2. Do you currently have programs designed to meet the health needs of your clients?

Yes No

If yes, briefly describe these programs:

3. Do you have any health programs that are specifically designed to serve women clients?

Yes No

If yes, briefly describe these programs:

4. Do you think these programs are well utilized by the women with disabilities in your community?

Yes No Not Sure

If no, do you have any idea why not?

5. Have the women clients you serve/represent made you aware of any specific health care needs for women who have disabilities?

Yes No

If yes, please explain:

6. Have you ever attempted to design or develop programs to meet these needs?

Yes No Not Sure

If yes, what happened?

Please enclose with this questionnaire information about your organization.

Appendix 5

Focus Group Questions

1. What does gynecological health care mean to you?
2. Are your gynecologic health care needs being met?
3. What does breast health care meant to you?
4. Are your breast health care needs being met?
5. What do you think are the barriers to care for women with disabilities?
6. Do you feel that there is a need for accessible gynecological and breast services for women with disabilities?
7. What kind of disabilities do you think would likely be represented in an accessible clinic?

Appendix 6

Participating Organizations

Diagnostic & Ambulatory Clinic of BC Women's Hospital and Health Centre

British Columbia Paraplegia Association

GF Strong Rehabilitation Centre

George Pearson Centre

Screening Mammography Program of British Columbia, BC Cancer Agency (BCCA)

Cervical Cancer Screening Program of British Columbia (BCCA)

Continence Clinic of BC Women's Hospital and Health Centre

Appendix 7

Responses to Question 1: What is Your Disability?

Cerebral palsy	46
Paraplegia	42
Quadriplegia	31
Multiple sclerosis	22
Impaired mobility	12
Rheumatoid arthritis	16
Mental health	13
Post polio	13
Spina bifida	12
Fibromyalgia	12
Brain injury	11
Blindness	10
Scoliosis	9
Seizure disorder	9
Osteoarthritis	9
Osteoporosis	8
Deafness	8
Chronic fatigue	7
Amputation	6
Muscular dystrophy	5
Arthrogryphosis	4
Cardiac disease	4
Asthma	4
Head injury	3
Hydrocephalus	3
Spinal muscular atrophy	3
Bipolar affective disorder	2
Vestibular disorder	2
Lupus	2
Neurofibromatosis	2
Myalgic encephalomyelitis	2
Bladder incontinence	1
Multiplex congenita	1
Irradiation	1
FAS	1
Behaviour problems	1

Epidermolysis bullosa	1
Dwarfism	1
Pituitary adenoma	1
Anarclipse	1
Depression	1
ALS	1
Degenerative disc disease	1
Chronic pain	1
Irritable Bowel Syndrome	1
Schizophrenia	1
Hip fusion	1

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Nous sommes aussi des femmes

Définir les obstacles aux soins
de santé pour les seins et ceux
d'ordre gynécologique que
connaissent les femmes handicapées

Dans quelle mesure les femmes handicapées en Colombie-Britannique sont-elles soumises à un dépistage pour le cancer du sein et le cancer du col de l'utérus? Les femmes handicapées qui ont participé à cette recherche ont souligné qu'un centre accessible aux personnes handicapées est nécessaire afin de surmonter les obstacles au dépistage.



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de la C-B pour la
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