• Making Us Visible •

Promoting Access to Breast Health and Breast Cancer Services for Lesbian and Bisexual Women

> A guide to delivering a workshop for health care and social service providers to increase their knowledge, skills and sensitivity in working with lesbian and bisexual women in the area of breast health and breast cancer



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By Cheryl Dobinson, Project Coordinator

About the Making Us Visible project:

"Making Us Visible: Promoting Access to Breast Health and Breast Cancer Services for Lesbian and Bisexual Women" was a two-year innovative health promotion project launched in September 2004 at Sherbourne Health Centre in Toronto. The project goals were to increase the capacity of lesbian and bisexual women to respond to the risk of breast cancer and to increase the capacity of the breast cancer community to respond to the needs of lesbian and bisexual women.

Making Us Visible addressed lesbian and bisexual women's breast health through two volunteer programs designed to increase community involvement and understanding. One program focused on developing culturally appropriate educational materials and the other on creating a series of volunteer-led breast health events for lesbian and bisexual women.

The project also worked to increase accessibility of breast cancer services through offering a support group for lesbian and bisexual women with breast cancer as well as developing a training program to increase knowledge and sensitivity for peer support volunteers when working with lesbian and bisexual women who have had a breast cancer diagnosis. This training was further developed into a workshop for a broad range of health care and social service providers and piloted throughout Ontario.



Making Us Visible was a partnership between Sherbourne Health Centre, Ontario Breast Cancer Community Research Initiative, Gilda's Club Greater Toronto, Willow Breast Cancer Support Canada, and the Metropolitan Community Church of Toronto.

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SECTION 1: The Making Us Visible Workshop Curriculum

- Introduction
- Advance Preparation
- The Curriculum
- *Tips for Using the Curriculum Based on Your Audience*
- Issues to Expect and Ideas for Handling Them

Introduction

This curriculum was developed in the summer and fall of 2006 by myself (Cheryl Dobinson, Project Coordinator for Making Us Visible: Promoting Access to Breast Health and Breast Cancer Services for Lesbian and Bisexual Women) and Danielle Vandezande of Willow Breast Cancer Support Canada. We developed the original version as a pilot workshop for Peer Support Volunteers at Willow Breast Cancer Support Canada and delivered it in August 2006. The Peer Support Volunteers were a wonderful and welcoming group and a lot was learned from their constructive feedback on how the workshop could be improved.

During the months of September and October 2006 I had the opportunity to offer the workshop in a variety of settings across Ontario, and to revise and fine-tune it as I learned from each session. I delivered the workshop in community health centres, cancer centres, university health centres and to broader groups of interested health care providers. I traveled to Hamilton, Windsor, Sudbury, Sault Ste Marie, and Kitchener, as well as offered the workshop in other settings in Toronto.

The final workshop as outlined in this manual is based on consolidating everything that was learned from delivering the workshop in all these settings.

A message from Anna Travers - Manager, LGBTT Program, Sherbourne Health Centre

The idea for the Making Us Visible project came about because a group of us had been involved with the Lesbians and Breast Cancer Project, a community-based participatory study conducted in Ontario in 2003. We had learned about queer women's experiences with cancer, the health care system, their sense of themselves as women and dykes and so much more and we wanted to put all that learning into a practical application and share it with others.

We applied to the Canadian Breast Cancer Foundation, Ontario Chapter for a Community Health Promotion Grant that would last two years. It had two areas of focus: 1) to develop resources for lesbian and bisexual women and for service providers that addressed breast health in this specific population, and 2) to develop and pilot support services for lesbian and bisexual women who have had a breast cancer diagnosis. This manual emerged from the work that was done to develop a training program to increase knowledge and sensitivity of service providers when working with lesbian and bisexual women in the area of breast health and breast cancer.

Our original intent was to develop and pilot a workshop with Peer Support Volunteers at Willow Breast Cancer Support Canada and then to finalize the workshop based on the evaluations and feedback from those participants. This plan changed when staff at Canadian Breast Cancer Foundation encouraged us to "take the show on the road" and deliver the workshop in additional settings across Ontario in order to provide training for more service providers and to further develop and revise the pilot version of the workshop. So in summer 2006 we began promoting the workshop province-wide and immediately the calls and emails started coming in. The Project Coordinator, Cheryl Dobinson, delivered the workshop to six different groups of service providers in Hamilton, Windsor, Sudbury, Sault Ste Marie, Kitchener and Toronto. We are very grateful to the people and organizations in these communities who invited us in and who made these workshops possible through coordinating the local logistics of promotion, venue, registration and more.

I want to thank all the people who helped with the Making Us Visible project – from the Steering Committee, the Resource Development Group and the Peer Education Group – you did yourselves and your community proud! For this piece of the project, a special thank you is due to Danielle Vandezande of Willow Breast Cancer Support Canada, who sat on the Steering Committee and who worked closely with Cheryl to develop the workshop module and deliver the initial pilot training at Willow. This manual is a reflection of a large piece of the work of the Making Us Visible project of which we are very proud. I hope it will be useful to those working in cancer services, health care, social services and beyond.

Advance preparation

Potential Audiences

A wide range of health and social service providers might be interested in and benefit from participating in this workshop, including:

- Breast cancer peer support staff and volunteers
- Breast cancer support group facilitators
- Members of breast cancer support teams
- Doctors, nurses and other health professionals (both those who work specifically in breast health or breast cancer and those whose work is broader)
- Breast screening program staff
- Radiologists, oncologists, surgeons, social workers, chemotherapists and others who provide direct service to breast cancer patients
- Students in health professions

Finding a Venue

In some instances, you may be delivering the workshop for or with the support of a specific organization, in which case that organization will most likely provide space for you to conduct the workshop. If you do not have a host organization providing space, you can try free or low cost options in your area such as community centres, community health centres, libraries, lesbian, gay, bisexual and transgender (LGBT) organizations, colleges or universities, or other appropriate local venues.

Promotion

Depending on whether you are offering this workshop to an existing group of service providers or more broadly, you will need different promotional tools.

If you are offering the workshop to an existing group of service providers, such as the staff and/or volunteers of a particular organization, you will likely need to provide a brief description of the workshop for internal distribution at the organization. (see Appendix A for a sample promotional poster.)

If you are offering the workshop more broadly and inviting any interested service providers to attend, you will need to create and distribute promotional materials. Promotion methods could include sending a notice by email and/or mail to local cancer service organizations, breast screening centres, women's health organizations, LGBT health service organizations, community health centres, cancer centres, and any other places in your community where service providers work with women in the areas of breast health and breast cancer.

You may want to have participants register with you in advance so you know how many people to expect.

Financial Considerations

It is possible to do this workshop on a very low budget. If you are able to access a free venue, and do not provide refreshments, the total cost should be under \$25. Here is a list of items you may want to budget for, depending on what level of funding you have available:

- Venue
- Photocopying handouts
- Nametags (stick-on address labels work well and are relatively inexpensive)
- Pens
- Markers
- Tape
- Index cards
- Flipchart paper (two large pieces minimum) if there is no chalkboard or whiteboard
- Refreshments (optional)

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Items Needed at the Workshop

- Name tags, markers, index cards, pens, flipchart or chalkboard
- Agenda written on a flipchart or chalkboard
- Guidelines written on a flipchart or chalkboard
- Copies of handouts for all participants

Handouts List

- Definitions (Appendix B)
- Terminology Suggestions (Appendix C)
- Busting Out: Breast Health for Lesbian and Bisexual Women brochure - www.sherbourne.on.ca/programs/programs-m.html
- Ways To Open The Door: Asking The Right Questions (Appendix D)
- Case Studies (Appendix E)
- Lesbian and Bisexual Women's Breast Health Resource List (Appendix F)
- Additional Resources for Service Providers (Appendix G)
- Evaluation Form (Appendix H)

You may also want to provide materials on local groups and services, such as cancer support groups for lesbian and bisexual women or LGBT health centres if these exist in your area.

Time

The full workshop described in this manual takes about three hours, including a 15 minute break. It is also possible to adapt it for 90 minute or two hour sessions if needed:

90 Minute Workshop (no break)

- 1. Introduction and welcome 10 minutes
- 2. Cultural competence 5 minutes
- 3. Definitions and assumptions 10 minutes
- 4. Lesbian and bisexual women's health 10 minutes - Brief brainstorm
- 5. Lesbian and bisexual women and breast health/ breast cancer 20 minutes
- 6. Ways to open the door Asking the right questions 15 minutes
- 7. Case scenarios Provide the handout but do not spend time working on the scenarios in the workshop (no time allotted)
- 8. Tips for inclusive practice 5 minutes
- 9. Referrals and resources 5 minutes
- 10. Questions 5 minutes
- 11. Evaluations 5 minutes

2 Hour Workshop (no break)

• As above, but add in the case scenarios (30 minutes)

Using the Curriculum

- In the curriculum that follows, any items which are not used in the 90 minute or two hour versions are printed in italics.
- The maximum time indicated after each section heading below is for the full section as it would be delivered in a three hour training.
- Notes and instructions to the trainer are printed in bold, while suggested wording for what the trainer would actually say to participants is printed in normal font.

The Curriculum

1. Introduction and welcome (10-20 minutes)

As people arrive, ask them to make a nametag for themselves, and invite them to help themselves to refreshments if provided.

Welcome everyone to the workshop and introduce yourself. Review the posted agenda.

Agenda

- 1. Introduction and welcome
- 2. Cultural competence
- 3. Definitions and assumptions
- 4. Lesbian and bisexual women' health
- 5. Lesbian and bisexual women and breast health/breast cancer
- 6. Ways to open the door Asking the right questions
- 7. Case scenarios
- 8. Tips for inclusive practice
- 9. Referrals and resources
- 10. Questions
- 11. Evaluations

This workshop was developed by the project "Making Us Visible: Promoting Access to Breast Health and Breast Cancer Services for Lesbian and Bisexual Women" which was based at Sherbourne Health Centre in Toronto from 2004-2006 with funding from the Canadian Breast Cancer Foundation, Ontario Chapter.

The goals of this interactive workshop are:

- to increase knowledge and sensitivity for service providers when working with lesbian and bisexual women in the area of breast health and breast cancer
- to increase the accessibility of breast health and breast cancer services for lesbian and bisexual women

Learning objectives:

- Participants will learn about the ways in which sexual orientation is relevant to health, and specifically to breast health and the breast cancer experience.
- Participants will learn about lesbian and bisexual women's breast health, including prevalence of specific risk factors and screening rates.
- Participants will be able to apply practical knowledge gained from this presentation in participant's own practice.

Review the posted guidelines and ask the group if they can agree to follow these guidelines.

Guidelines¹

- 1. Respect the confidentiality of personal information shared
- 2. We can agree to disagree
- 3. Use "I" statements rather than "You" statements
- 4. Each person is responsible for their own comfort (no break)
- 5. Ask questions and be willing to take risks
- 6. There are no stupid questions
- 7. Honour our time by keeping the schedule

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¹ This set of guidelines is adapted with permission from Removing the Barriers: Providing Culturally Competent Care to Lesbians and Women Who Partner with Women, 1997-2004. Copyright The Mautner Project, the National Lesbian Health Organization and the United States Department of Health and Human Services.

Participant introductions

If the participants do not already know each other, you may want to go around the room and have people say their name and where they work or volunteer.

With any group of participants you can also ask people to share either:

- 1. What brought you to the training? or
- 2. Why you think this training is important for your work?

Assumptions for training²

- There is knowledge in the room we all come with different relationships to lesbian and bisexual women. Some of us may have a little knowledge and some may have a lot.
- You deliver quality care to women.
- You are interested in exploring ways to increase your competence to provide better care to all women.
- If you are already providing care to women, you have lesbian and bisexual women clients, even if they have not revealed themselves as such.

Hand out index cards and explain that these are for questions or comments and will be collected later on.

2. Cultural competence² (5-10 minutes)

Ask if anyone knows what cultural competence means. If there are some nods or yeses, ask if anyone would like to share what they understand it to mean.

Cultural competence is:

- being responsive to and respectful of cultural factors and other differences that influence the attitudes, behaviours and life experience of every patient or client³
- relevant to all types of cultural and social difference, not just sexual orientation, so it includes things like race, ethnicity, religion, age, ability, and gender
- a flexible and inclusive approach to every client
- reducing or eliminating barriers = improving accessibility and acceptability of services
- individually: a set of behaviours, attitudes and knowledge that enable a person to interact effectively with people who are different from them
- institutionally: a set of behaviours, attitudes and knowledge that enable an organization to serve people of different cultures in respectful and appropriate ways
- a journey, not a destination

Cultural competence training is about developing skills, not about changing people's values or beliefs

- regardless of your values or beliefs about lesbian and bisexual women, you can provide culturally competent care to all women you serve
- you do not have to agree with someone's behaviour or beliefs to provide them with respectful, sensitive and well-informed care

² The assumptions for training and the cultural competence section are adapted with permission from Removing the Barriers: Providing Culturally Competent Care to Lesbians and Women Who Partner with Women, 1997-2004. Copyright The Mautner Project, the National Lesbian Health Organization and the United States Department of Health and Human Services.

³ In this manual the words "patient" and "client" are used interchangeably to describe a person receiving care or service from a health care or social service provider.

Benefits of cultural competence:

- Increased access to services
- Better communication and rapport
- Greater client satisfaction
- More word of mouth referrals
- Greater provider satisfaction

3. Definitions and assumptions (10-15 minutes)

a. Definitions

- i. Provide the Definitions handout (Appendix B)
- ii. Briefly review the definitions by reading them out.
- b. Respectful language use
 - i. Provide the Terminology Suggestions handout (Appendix C)
 - ii. This handout provides more detail about respectful language use and the reasons some terms are preferred over others. You will notice that in this workshop I will use the terms "sexual orientation" and "sexual identity," as both are appropriate and respectful options.
- c. Diversity in identity
 - i. There are many different ways that women who are attracted to women may identify. They may identify as lesbian, bi, bisexual, queer, gay woman, dyke, or in others ways, or they may not use a sexual identity label at all.

The key thing to consider with regard to language use with each individual woman is to follow her lead in terms of how she talks about herself and her life and then use the language she uses.

d. Diversity of acronyms

In the definitions section we included the acronym "LGBT." Different organizations and locations may use different acronyms. These may include any or all of the following letters, and possibly others which have not been captured here:

LGBTTTIQQ - lesbian, gay, bisexual, transgender, transsexual, two-spirit, intersex, queer and questioning

- e. Sexual behaviour vs. sexual identity
 - i. People's sexual behaviour and sexual identity may not always match up in the ways we expect. For example: A woman may identify as bisexual but only be sexually involved with a female partner. Women who are lesbian-identified may have had sexual relationships with men.
 - ii. Sexuality has many aspects sexual behaviour, sexual attraction and sexual identity are some of the parts and any of these parts may change over time.
- f. We should not make assumptions about:4
 - i. who lesbian and bisexual women are (they are diverse in every way possible)
 - ii. with whom a patient has important relationships
 - iii. what anyone does sexually
 - iv. what their issues of concern may be
 - v. what their relationship to health risk factors may be

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⁴ This list is adapted with permission from Removing the Barriers: Providing Culturally Competent Care to Lesbians and Women Who Partner with Women, 1997-2004. Copyright The Mautner Project, the National Lesbian Health Organization and the United States Department of Health and Human Services.

4. Lesbian and bisexual women's health (10-15 minutes)

What are the ways that sexual orientation could be relevant for lesbian or bisexual women's health?

Ask people to brainstorm, and then go over the list below (which is not meant to be exhaustive) to cover any topics which did not come up in the brainstorm. *(keep the brainstorm brief in the 90 minute and 2 hour versions)*

- 1. Sexual practices and safer sex practices
- 2. Relationships
 - a. Who is important to include in their care
 - b. Who can visit them in the hospital
 - c. Availability of appropriate support services for dealing with issues between partners (ie. couples counseling) or partner abuse
- 3. Experiences of anti-gay violence, harassment or discrimination
 - a. Consequences for physical and mental/emotional health
- 4. Parenting options and needs including different ways of bringing children into families such as reproductive technologies, adoption, children from past relationships
- 5. Issues with family of origin estrangement, lack of support, conflict around health care decision making between family and partner
- 6. Legal issues with families both family of origin and the families they create
- 7. Mental health can include issues around coming out, being closeted, isolation, identity development processes, self esteem and self care
- 8. Community of support this may be lesbian/bisexual specific or may be missing for some women
- 9. Homophobia and biphobia can lead to lesbian and bisexual women avoiding medical care or delaying seeking care.

How homophobia and biphobia affect health care:

- Some lesbian and bisexual women have had negative experiences in health care settings such as poor treatment, refusal of service, negative verbal or nonverbal reactions, misinformation, hostility, exclusion of partner, and rough treatment.
- Some lesbian and bisexual women may cope with having had negative experiences or with the fear of having such experiences by not disclosing their sexual orientation, avoiding seeking care, or not talking about social support networks, partners, sexual practices, specific support or information needs, or any other items related to sexual orientation.

5. Lesbian and bisexual women and breast health/breast cancer (20 minutes)

Now let's talk about breast health and breast cancer specifically in relation to lesbian and bisexual women. What are the issues?

a. Breast health education

Very few materials on breast health focus on, or are even inclusive of, lesbian and bisexual women

- i. Even if most of the breast health information is the same, it needs to get to lesbian and bisexual women. Targeted resources are one way to reach lesbian and bisexual women.
- ii. Lesbian and bisexual women may have some unique issues and feelings about their breasts that are not addressed in other materials or educational efforts. For example: Lesbian and bisexual women in relationships with women may feel concern for a partner's breast health as well as one's own, more masculineidentified or butch women may have ambivalent feelings about having breasts and may be reluctant to pay attention to or care for their breasts.

iii. Provide the Busting Out: Breast Health for Lesbian and Bisexual Women brochure as an example of a targeted resource.

b. Risk factors

Lesbian and bisexual women have higher rates of some breast cancer risk factors than heterosexual women. These risk factors are:

- i. having no biological children or giving birth to first child after age 30
- ii. high alcohol consumption
- iii. high body weight

There is a popular misconception that lesbians in particular are at dramatically higher risk for breast cancer. Some writers have mistakenly stated that 1 in 3 lesbians will get breast cancer compared to 1 in 9 women in the general population. This is based on media misinterpretations of an early 1990s research review of the differences in rates of some breast cancer risk factors between lesbians and heterosexual women. Preliminary reviews of a very limited body of research suggested that lesbians may have 2-3 times the rates of certain risk factors, and this was taken up in the media as meaning that lesbians would have 2-3 times the incidence of breast cancer. This is not true.

Even if lesbians had 2-3 times higher rates of risk factors (which more recent research indicates is not the case – the differences are much smaller), this still would not mean that rates of breast cancer would be 2-3 times higher. Rates of risk factors do not translate directly into rates of breast cancer.

Simply being lesbian or bisexual does **not** put a woman at higher risk for breast cancer. As a group, lesbian and bisexual women do have higher rates of some breast cancer risk factors than heterosexual women. However, each individual lesbian or bisexual woman will have her own particular relationship to these and other risk factors, and her sexual orientation in and of itself is not a risk factor for breast cancer.

c. Breast cancer rates

What do we know about actual rates of breast cancer among lesbian and bisexual women? There is very little research on this, but some evidence of a slightly higher rate.

A 2002 study of 93311 US women aged 50-79 showed a higher incidence of breast cancer in lesbian and bisexual women⁵. The following rates of breast cancer were reported, based on behavioural definitions of sexual orientation:

- 1. 4.9% of heterosexual women
- 2. 8.4% of bisexual women
- 3. 5.8% of lifetime lesbians (sex only with women ever)
- 4. 7.0% of adult lesbians (sex only with women after age 45)

d. Screening

Studies have shown that lesbian and bisexual women as a group do not practice screening and preventative behaviours around their health as often as heterosexual women, including having clinical breast exams and mammography.

- i. Why do you think this might be? (ask participants if they have any ideas)
 - 1. Homophobia and biphobia can lead to lesbian and bisexual women avoiding medical care or delaying seeking care. This also means they may not seek help for breast problems until they are quite serious.
 - 2. Less contact with the medical system around routine gynecological/ reproductive health care than heterosexual women

5 Valanis BG, Bowen DJ, Bassford T, Whitlock E, Charney P, Carter RA. Sexual orientation and health: comparisions in the Women's Health Initiative sample. Arch Fam Med. 2000;9:843-853. 15

e. Specific issues following a breast cancer diagnosis

This section draws in large part from themes that emerged in the Lesbians and Breast Cancer Project report "Coming Out About Lesbians and Cancer." (http://dawn.thot.net/lbcp/)

Specific issues and experiences for lesbian and bisexual women with breast cancer may include:

- Disruption of "body sameness" in same sex relationships
- Lack of family support due to estrangement based on sexual orientation
- Support could come from other places, such as LGBT communities or chosen family
- The "could be me" factor, where female partners and other lesbian and bisexual women may identify very strongly with the possibility of getting breast cancer. This can have both positive effects (understanding and support) and negative effects (distancing and fear).
- Lack of appropriate support for female partners and children and lack of recognition for same-sex partners in medical or support settings
- Fallout from treatment:
 - Short hair may be more accepted in lesbian and bisexual women's communities
 - Programs that offer make-up tips to help women feel better about their appearance during treatment may be right for some lesbian and bisexual women but may not fit at all for others
 - Loss of physical strength may be particularly challenging to a lesbian or bisexual woman's identity and lifestyle
 - Breast loss there are different views on whether this matters more or less for lesbian and bisexual women compared to heterosexual women, as well as ideas around breast prostheses or reconstruction related to gender identity and presentation
- Feelings of already limited options for dating or relationships being reduced further
- Heterosexism, homophobia and/or biphobia in medical or support settings. This can include reactions such as disbelief, disgust, poor treatment, discomfort or assumptions of heterosexuality, such as being asked about one's husband.
- Decisions around coming out or not coming out in medical or support settings. This can include weighing whether disclosing lesbian or bisexual identity will make things better or worse.

BREAK – 15 minutes

Remind people to write questions on their index cards, which will be addressed at the end of the workshop.

6. Ways to open the door: Asking the right questions (15 minutes)

Why is it important to open the door to talking about sexual orientation with your clients or patients?

- Because of all the things we've been talking about so far in terms of lesbian and bisexual women's unique issues and experiences
- Because being lesbian or bisexual is an important part of some women's lives that should be validated and supported
- Research indicates that lesbian and bisexual women want to have clear opportunities to disclose their sexual orientation so they don't have to worry about coming out/not coming out, trying to figure out if a provider is LGBTpositive, or creating a moment to disclose

- Lesbian and bisexual women have said that they don't want to be the ones to have to bring it up all the time
- To enable you to provide the best care possible for the whole person

There are a range of ways of opening the door to talking about sexual orientation

- There is no one right way that fits for every person, relationship and setting
- It is helpful to be familiar with a range of options, from direct questions to creating a safe/LGBT positive atmosphere.

Provide the Ways to Open the Door: Asking the Right Questions handout (Appendix D) and read it to participants.

If you ask a direct question about sexual orientation you need to be able to explain why you're asking (based on the reasons above) and that you ask of everyone. You may want to say that a person doesn't have to answer the question, but that you want to provide the opportunity for them to talk about these things if they choose.

Language tips:

- Use gender neutral terms
- Ask if patient or client is single, married or partnered
- Use the word "partner" and, if appropriate, ask the gender or name of the person's partner
- Don't assume that partner = same sex partner
- Ask about sexual identity and/or sexual activity, depending on what's relevant
- If asking about or talking about sexual activity, say "sexual activity" not "sexual intercourse" or "have sex." Don't assume sex = penis in vagina. If this is the only type of sex you're talking about, make that clear.

7. Case scenarios (o-30 minutes)

This section is not included in the 90 minute workshop.

Divide participants into small groups and provide each group with a case scenario to review and discuss. Each case scenario comes with 2-3 questions for groups to answer. Ask groups to make some notes about their discussion for reporting back to the larger group.

After groups have finished discussing their scenarios, have each group read out their case scenario and share their answers to the questions with the larger group.

Allow 10-15 minutes for the small group discussions and 15-20 minutes for the groups to report back.

8. Tips for inclusive practice (5-20 minutes)

- Provide health resource materials for lesbian and bisexual women on breast health/ breast cancer and other health issues
- Show visible signs of being LGBT friendly, including posters, waiting room magazines and materials, rainbow symbols (which represent LGBT communities) or LGBT positive space stickers (see www.positivespace.utoronto.ca for a downloadable sticker)
- Use inclusive intake forms and questions which allow women to disclose their sexual orientation in a safe way
- Educate yourself and your organization about lesbian and bisexual women's issues
- Post a visible nondiscrimination policy which mentions sexual orientation
- Be aware of lesbian and bisexual specific cancer support groups and other local resources for referrals

Small group activity:

Divide participants into small groups and ask them to answer the following questions:

- What are two or more changes you are willing to make in how you provide services?
- What might help you make these changes?
- What might hinder this?
- What support and resources can you draw on in overcoming obstacles?

Allow 5 minutes for providing the list of tips, then 15 minutes for the small group discussions.

9. Referrals and resources (5 minutes)

Provide handouts – Lesbian and Bisexual Women's Breast Health Resource List (Appendix F) and Additional Resources for Providers (Appendix G) and share any specific local information on support groups or other relevant services.

10. Questions – from index cards and other (10 minutes)

Ask people to hand in their index cards with any questions they have written on them. Address these questions, if any, and take questions verbally as well.

11. Evaluations (5 minutes)

Hand out evaluation form and ask participants to fill it in and return to you.

Thank everyone for attending.

Tips for using the curriculum based on your audience

When using the training for peer support volunteers working with women who have had a breast cancer diagnosis:

- Spend less time on items related to risk and screening and more time on the experiences of lesbian and bisexual women who have had a cancer diagnosis.
- Use case scenarios which relate specifically to peer support work.

When using the training for people working in health care generally:

- If the people you are presenting to do not work specifically in breast health/breast cancer, you may sometimes need to bring the focus back to breast health/breast cancer and remind participants of how the things you are talking about relate specifically to breast health and breast cancer.
- It may be helpful to frame the workshop as both general cultural competency for working with lesbian and bisexual women as well as a workshop on breast health and breast cancer issues for lesbian and bisexual women, as much of what is covered is relevant for other areas of lesbian and bisexual women's health as well.

When using the training for people working in breast health and breast cancer specifically:

• In this setting, it is likely that you will primarily be bringing the lesbian and bisexual specific information, while participants will bring their focus on breast health and breast cancer.

Issues to Expect and Ideas for Handling Them

1. Questions about trans people

People may ask questions about what transgender means or how transgender is different from transsexual. They may ask why the workshop only covers lesbian and bisexual women, and not trans women or trans people. They may ask about risk factors, screening and breast cancer rates for trans men and women.

Possible responses:

- a. It can be helpful to have definitions for transgender and transsexual available, even though they are not included in the definitions handout.
- b. Definitions:
 - i. **Transsexual:** A person who self identifies and desires to live and be accepted as a member of the gender other than the one assigned to them at birth. Many, although not all, transsexual people change (or want to change) their bodies to better match their gender identity through hormone therapy, hair removal, and/or surgery to change the physical appearance and function of sexual characteristics such as breasts/chests and genitals.
 - ii. Transgender: This word is sometimes used as an umbrella term to refer to a range of individuals whose gender identity and/or gender expression differs from the gender they were assigned at birth. In this use of the word, it includes a wide range of identities such as transsexual, drag queen, drag king, genderqueer, cross-dressers and other ways people may identify outside of the traditional genders of woman and man. At other times, the word transgender is used in a more specific way to refer to people whose gender identity and/or gender expression does not fit the traditional genders of woman and man, but who do not identify as transsexual.
- c. This particular workshop is about sexual orientation, not gender identity. Breast health issues for trans people can be quite different due to surgery, hormones and experiences of transphobia in health care. This workshop came out of a community research project with lesbian and bisexual women and is specific to these communities.
- d. There is little research on trans people's health, so we don't know about their rates of risk factors, screening or breast cancer rates.
- e. Some excellent resources for people who want to know more about this specific area are:
 - i. www.vch.ca/transhealth/resources/library/tcpdocs/consumer/medicalcancer.pdf
 - (Consumer information on trans people and cancer)
 - ii. www.vch.ca/transhealth/resources/library/tcpdocs/guidelines-primcare.pdf (Clinical guidelines, with a section on breast cancer)

2. "Why do we need labels? Aren't we moving away from labels anyway?"

Possible responses:

- a. First of all, labels are words which help us understand or explain things. Most of us use many labels in our everyday lives we may refer to ourselves as women or men, mothers or fathers, husbands or wives, partners, doctors, nurses, breast cancer survivors, tennis players, dancers and so on...
- b. For some people, sexual orientation labels are important to who they are. Whether you like sexual orientation labels or not, many people use and value them. It is important to acknowledge and respect people's use of language around their sexual orientation.

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3. Belief that focusing on sexual orientation is divisive of women

Possible responses:

- a. There are many differences between women. Ignoring them does not help women get the care and support they need.
- b. Refer back to the cultural competence framework.

4. Discomfort with asking direct questions about sexual orientation

Possible responses:

- a. People may frame this as not wanting to be intrusive or to make the person being asked uncomfortable. But generally this is more about the comfort level of the person asking and if they feel discomfort about talking about sexual orientation or about knowing someone's sexual orientation.
- b. In the Lesbians and Breast Cancer Project report "Coming Out About Lesbians and Cancer," (http://dawn.thot.net/lbcp/) women indicated that they wanted to be asked about their sexual orientation.

5. "We treat everyone the same"

Possible responses:

- a. Refer back to the cultural competence framework and the importance of having a flexible and inclusive approach to every client.
- b. Discuss how providing good care does not mean treating everyone the same. If I treat everyone the same, but that means that I ask every woman about her husband, this is not culturally competent care.

6. "Breast cancer is devastating to any woman, not just to lesbian and bisexual women."

Possible responses:

- a. Yes, but that doesn't mean there aren't some specific issues for lesbian and bisexual women that are unique.
- b. Discuss the ways in which different women may have specific issues related to breast cancer, such as:
 - young women and fertility issues
 - parents and concerns about the impact of cancer on their children
 - single women and concerns about dating/future relationships
 - women living in rural or remote areas who have to travel for treatment
- c. There are many ways in which various aspects of a woman's identity and experience can have impact on her experience of breast cancer.

SECTION 2:

APPENDICES

Appendix A - Promotional Poster

Appendix B - Definitions

Appendix C - Terminology Suggestions

Appendix D - Ways To Open The Door: Asking The Right Questions

Appendix E - Case Studies

Appendix F - Lesbian and Bisexual Women's Breast Health Resource List

Appendix G - Additional Resources for Service Providers

Appendix H - Evaluation Form

Appendix A: Promotional Poster

Making Us Visible:

Promoting Access to Breast Health and Breast Cancer Services for Lesbian and Bisexual Women

A Workshop for Service Providers



The goal of this workshop is to increase knowledge and sensitivity for service providers when working with lesbian and bisexual women in the area of breast health and breast cancer.

Through information sharing and interactive exercises, the workshop will cover:

- why sexual orientation is relevant to health, breast health and the breast cancer experience
- how to talk to women about sexual orientation
- risk factors for breast cancer which are of particular relevance to lesbian and bisexual women
- rates of screening among lesbian and bisexual women
- the impact of homophobia on lesbian and bisexual women's health and health care
- appropriate resources and referrals

Questions and discussion will be welcomed and encouraged!

When:	Tuesday,	September	12,	2006	1:00-4:00pm

Where: Sherbourne Health Centre, 333 Sherbourne Street, Toronto

Facilitator: Cheryl Dobinson, Sherbourne Health Centre, Toronto

To register for this <u>FREE</u> workshop, or for more information, contact Cheryl at <u>cdobinson@sherbourne.on.ca</u> or (416) 324-4180

Appendix B: Definitions

Lesbian: A woman whose sexual and romantic interest is towards other women.

- Gay: A person whose sexual and romantic interest is towards people of the same sex. Can be used by men and women, but is increasingly used to refer only to men.
- Homosexual: Someone who is sexually and romantically attracted to people of the same sex. Because the term is associated historically with a medical model of homosexuality as a sickness, most people prefer words like gay or lesbian to describe themselves.
- Bisexual: Someone who is sexually and romantically attracted to men and women.
- LGBT: Acronym standing for Lesbian, Gay, Bisexual and Transgender.
- Queer: A term used in the past as a derogatory term for effeminate and/or gay males. It has been reclaimed by some people, and in contemporary usage is an inclusive umbrella term for people who are lesbian, gay, bisexual and transgender (LGBT). Some members of these communities resist this usage, and reject its application to them. However, many LGBT people believe that using the umbrella term queer is a positive way to reclaim a term that was previously used against them, stripping the term of its power to insult.
- Coming out: 1. The developmental process whereby gay, lesbian and bisexual people recognize their own sexual orientation.
 2. Can refer to disclosure of one's sexual orientation.
- Homophobia: Prejudice and discrimination against lesbians, gays and bisexuals; against same-sex sexual attraction, expression and relationships.
- Heterosexism: The social, cultural and institutional privilege of heterosexual orientation. It includes the belief that heterosexuality is superior to any other forms of sexual orientation and the assumption that everyone is heterosexual unless otherwise indicated.
- Biphobia: Discrimination and prejudice against bisexuals. There is a lot of overlap between biphobia and homophobia and bisexual people often experience the effects of both.

Appendix C: Terminology Suggestions

Confused About What To Say?

Due to experiences with homophobic prejudice and discrimination, lesbians and bisexual women are often quite sensitive to any signal that indicates that a health care provider may not be familiar or comfortable with same sex relationships and sexual behaviour.

As we have seen with many different cultural groups, self-referential language evolves as issues of status and identity change. One way you can demonstrate your willingness to provide lesbian and bisexual affirmative care is by the language you use. Here are some terms that generally fit what is preferred right now, and that will increase your confidence that your language is culturally competent:

"Lesbian," "Gay," or **"Bisexual"** are preferred over **"homosexual."** Homosexual used either as a noun or an adjective is too clinical, and for your clients it may connote anti-gay attitudes.

"Queer" is controversial. Women who use this term in reference to themselves are "reclaiming" it from being used as a tool of oppression. Some women still respond strongly to the negative connotations of "queer." Given with mixed response to this term on the LGBT community, you will be safest to use phrases such as "lesbian, gay, bisexual, and transgender" or "LGBT," and to personally note the connotation a client who uses the term "queer" seems to give it.

"Partner" is generally preferred to **"lover," "friend,"** or **"roommate." "Partner"** is a good term to use with all clients. Use of terms like "friend" or "roommate" communicates a discomfort or unwillingness to regard a same sex partner with the same validity as an opposite sex partner.

"Sexual identity" and **"sexual orientation"** are the terms preferred to **"sexual preference." "Sexual orientation"** developed in response to the phrase **"sexual preference"** to combat arguments that sexuality is a choice and that homosexuality can be **"treated"** to change it to heterosexuality. Today **"sexual preference"** is often perceived as being a term that invalidates how true a lesbian, gay or bisexual identity feels for the individual. You can generally use both **"sexual identity"** and **"sexual orientation"** with your clients.

It is important to understand the difference between **"homophobia"** and **"heterosexism." "Homophobia"** focuses on prejudices against lesbian, gay and bisexual people from individuals. It refers to overt negative reactions from people. **"Heterosexism"** changes the focus to the larger culture, to heterosexist discrimination and assumptions. **"Heterosexism"** has both external manifestations as well as internally felt experiences of shame for some people with a non-heterosexual identity.

Be aware of how you use **"family."** Are you referring to **"family of origin"** or **"family of choice"**? Because of heterosexism, including forms of rejection from members of the family in which one was raised (family of origin), people may create familial relationships among friends (family of choice). Do not assume that members of your client's family of origin are who she considers family. Frequently partners, former partners, friends, or even supportive members of others' families feel and operate as family to lesbian and bisexual women. Inquire about who is in your client's **"family of choice"** as you determine their real support network.

⁶ This handout is adapted with permission from Removing the Barriers: Providing Culturally Competent Care to Lesbians and Women Who Partner with Women, 1997-2004. Copyright The Mautner Project, the National Lesbian Health Organization and the United States Department of Health and Human Services.

Appendix D: *Ways to Open the Door: Asking the Right Questions*

Sample Questions for Intake Forms:

- 1. How would you describe your sexual orientation? (leave space for client to write an answer)
- 2. Sexual identity:
 - a. Straight/heterosexual;
 - b. Lesbian
 - c. Gay
 - d. Bisexual
 - e. Other (leave space for client to write)
 - f. Don't know

Sample Questions for Client Interviews:

- 1. "Are you involved in a significant relationship at this time? (if yes) tell me about your relationship." ⁷
- 2. "Tell me about the people who are important to you. Do you feel like you get enough support from family and friends?" ⁸
- 3. Are you involved in any groups or communities that are important to you or that provide support? (Can prompt with examples: a religious group, an activity-based group, a neighbourhood group, a lesbian group, a group for women of colour etc.)
- 4. At (name of organization) we try to respond to all the things women may face to be able to connect you with services and resources to best meet your needs. For example – services and resources for young women, women of specific cultures, lesbian and bisexual women, women of colour, women with disabilities and other groups of women. Are there any particular needs you have around connecting with other women, services or resources that might be more specifically relevant to you?
- 5. "In order for us to best support you, I'm going to ask a few questions. Some of the questions won't relate to you, but I want to make sure I'm connecting you with all the services and resources that make sense..." Then ask a series of questions: "do you identify with a particular ethnic or cultural group, are you a lesbian or bisexual or trans woman, do you have a disability, do you have financial needs, what is your housing situation? your age ... etc."

²⁵

⁷ Removing the Barriers: Providing Culturally Competent Care to Lesbians and Women Who Partner with Women, 1997-2004. Copyright The Mautner Project, the National Lesbian Health Organization and the United States Department of Health and Human Services.

⁸ Lesbians and Breast Cancer Project Team. 2004. Coming Out About Lesbians and Cancer. Toronto: Ontario Breast Cancer Community Research Initiative. http://dawn.thot.net/lbcp/

Appendix E: *Case Studies*

- 1. Ann calls a breast cancer support line and in the conversation she discloses that she has a female partner. The support worker thanks her for sharing that she is a lesbian and asks if there are any specific resources or information she would like for lesbians with breast cancer. Ann interrupts to say that she's not a lesbian.
 - What assumption has the support worker made?
 - What could she have done differently?
 - How could she repair this relationship?
- 2. Zara is a client who has recently been diagnosed with breast cancer. When at an appointment with a new practitioner, she does not indicate her marital status on the intake form. The practitioner notices that she keeps referring to her friend, Leah, who is in the waiting room. ⁹
 - Why might it be helpful for the doctor to ask Zara if she would like to invite Leah into the room?
 - Would it be useful for the doctor to know whether Leah is Zara's partner? Why or why not?
 - Why kinds of things could the doctor say or do that would indicate openness to the potential that they might be a couple?
- 3. Angela was diagnosed with breast cancer and has not returned for treatment because she has fears about how her oncologist will react to her being a lesbian. She is worried about the possible impact of revealing her sexuality, but it is important to her that she is open about who she is. Angela's sister convinces her to meet with an oncologist and this is her first visit.
 - How important is it for the oncologist to know explicitly that Angela is a lesbian?
 - How might the oncologist signal that it is safe for Angela to come out?
 - What sorts of things might Angela say to 'test the waters'? What could the oncologist be listening for?
- 4. During an appointment, Jas tells her nurse that she is worried about getting breast cancer because she is bisexual and has heard that lesbian and bisexual women are at higher risk for the disease.
 - How would you suggest that the nurse explain the relationship between sexual identity and breast cancer risk to Jas?
 - What information could the nurse provide to help Jas better understand her risk?
- 5. Helena calls a breast cancer support line because she wants to talk about her experiences as a lesbian with breast cancer and to find out whether there are any groups, resources or referrals for her as a lesbian but she doesn't tell the phone line worker this. She has experienced homophobia in the past with health care providers and in a support group for women with breast cancer. She is reluctant to come out unless it feels very safe to do so, even though she wants to talk about these things.
 - How could the phone line worker let Helena know that it is safe to come out?
 - What sorts of things might Helena say to 'test the waters'? What could the worker be listening for?
 - How can the phone line worker create an environment in every call which is open so that Helena and others would know it is safe to come out?

9 Case studies 2 and 3 are adapted with permission from Removing the Barriers: Providing Culturally Competent Care to Lesbians and Women Who Partner with Women, 1997-2004. Copyright The Mautner Project, the National Lesbian Health Organization and the United States Department of Health and Human Services.

Facilitator Notes for Case Studies

Case study 1:

- The assumption the support worker has made is that if a woman has a female partner that she identifies as lesbian. Ann may identify as bisexual, as gay, as queer or in some other way.
- The support worker could have used the language Ann used to talk about her partner, and perhaps thanked Ann for sharing information about her relationship and asked if she was interested in resources or information for women in relationships with women.
- The support worker could apologize for assuming what Ann's sexual identity was and let her know that her intent was to be open around sexual identity and to provide resources and information appropriate to Ann's needs.

Case study 2:

- It would be helpful for the doctor to ask Zara if she would like to invite Leah into the room because she is referring to Leah a lot, it seems that Leah is an important person in her life, and she may want the option for Leah to be involved in her care.
- It would be useful for the doctor to know whether Leah is Zara's partner in order to better understand Leah as a whole person and particularly if it is important to Leah for the doctor to know about her relationship.
- Refer to the Ways to Open the Door: Asking the Right Questions handout and the language and inclusivity tips on page 17.

Case study 3:

- It is important for the oncologist to know that Angela is a lesbian because Angela wants to be open about this part of who she is.
- Angela might talk about her partner or past partners using gender neutral language, she might mention LGBT events or groups, or she might talk about the importance of being open about who she is in the world.
- Refer to the Ways to Open the Door: Asking the Right Questions handout and the language and inclusivity tips on page 17.

Case study 4:

- This case provides a chance for workshop participants to explain in their own words the information on lesbian and bisexual women and breast cancer risk as outlined on page 15.
- The nurse could provide Jas with some of the resources listed in Appendix F.

Case study 5:

- Helena might talk about her partner or past partners using gender neutral language, she might ask if the worker has information on resources for specific groups of women, or she might talk about having had negative experiences with health care providers or in a support group in a general way without revealing the homophobic aspect of the experiences.
- Refer to the Ways to Open the Door: Asking the Right Questions handout and the language and inclusivity tips on page 17.

Appendix F: Lesbian and Bisexual Women's Breast Health Resource List

Websites - Lesbian and Bisexual Specific

- Lesbians and Cancer: Resources & Support (Ontario) http://lesbiansandcancer.com
- The Lesbians and Breast Cancer Project (Ontario) http://dawn.thot.net/lbcp/
- The Mautner Project For Lesbians with Cancer (US) www.mautnerproject.org
- Cancer in Women Who Have Sex With Women www.gayhealthchannel.com/wswcancer/

Websites - General

- Imaginis The Breast Health Resource (USA) www.imaginis.com
- Ontario Breast Screening Program www.cancercare.on.ca/index_breastScreening.htm
- The Healthy Breast Program A Naturopathic Resource www.healthybreastprogram.on.ca/
- Breast Cancer Care (UK) www.breastcancercare.org.uk/Breasthealth

Books - Lesbian and Bisexual Specific

- Aslin, Maureen; Brown, Barbara; Carey, Betsy. (2003). *My Breasts, My Choice: A Photographic and Narrative Journey*. Toronto: Sumach Press.
- Brownworth, Victoria (Ed.) (2000). *Coming out of Cancer: Writings from the Lesbian Cancer Epidemic*. Seattle: Seal Press.
- Butler, S. and Rosenblum, B. (1991). *Cancer in Two Voices*. San Francisco: Spinsters Book Company.
- Lorde, Audre (1988). A Burst of Light. New York: Firebrand Books.
- Lorde, Audre (1980). *The Cancer Journals*. San Francisco: Aunt Lute Books.

Books - General

- Love, Susan. (2000). *Dr. Susan Love's Breast Book, 3rd edition*. Perseus Publishing, Cambridge, MA.
- Kaur, Sat Dharam. (2003). *The Complete Natural Medicine Guide to Breast Health*. Toronto: Robert Rose.

Films - Lesbian and Bisexual Specific

- *Coming Out Again: Lesbians Speak Out About Cancer.* (2006) DVD. Ramsay Media (25 minutes, documentary)
- My Left Breast. (2000) VHS. Pope Productions Ltd. (57 minutes, documentary)

Resources - Environmental Issues

- *Exposure: Environmental Links to Breast Cancer*. (1997). Butterfield and Zuckerman, in association with Women's Healthy Environments Network. Toronto. (53 minutes, documentary)
- Steingraber, Sandra. (1997). *Living Downstream: An Ecologist Looks at Cancer and the Environment*. New York: Addison-Wesley Publishing Company.
- State of the Evidence: What is the Connection Between the Environment and Breast Cancer? www.breastcancerfund.org

Appendix G: Additional Resources for Service Providers

Lesbian and Bisexual Women's Breast Health and Screening Behaviour

Cochran SD, Mays VM, Bowen D, Gage S, Bybee D, Roberts SJ, Goldstien RS, Robison A, Rankow EJ, White J. *Cancer-Related Risk Indicators and Preventive Screening Behaviors Among Lesbians and Bisexual Women*. American Journal of Public Health 2001; 91: 591-597.

Diamant AL, Wold C, Spritzer K, Gelberg L. *Health Behaviors, Health Status, and Access to and Use of Health Care.* Archives of Family Medicine 2000; 9:1043-1051.

Dibble SL, Roberts SA. *Improving Cancer Screening Among Lesbians Over 50: Results of a Pilot Study*. Oncology Nursing Forum 2003; 30: 71-79.

Koh AS, Diamant A. *Use of Preventative Health Behaviors by Lesbian, Bisexual, and Heterosexual Women: Questionnaire Survey.* The Western Journal of Medicine 2000; 172: 379-385.

Rankow EJ. Breast and Cervical Cancer Among Lesbians. Women's Health Initiative 1995; 5: 123-129.

Valanis BG, Bowen DJ, Bassford T, Whitlock E, Charney P, Carter RA. *Sexual Orientation and Health: Comparisons in the Women's Health Initiative Sample*. Archives of Family Medicine 2002; 843-853.

Additional Education and Training Resources for Service Providers

Canadian Resources:

Rainbow Health Educational Toolkit http://www.rainbowhealthnetwork.ca/node/24

LGTB Health Matters, Education and Training Resource http://www.lgtbcentrevancouver.com/pdf_s/theManual_vFinal.pdf

US Resources:

Gay and Lesbian Medical Association Guidelines for Care of Lesbian, Gay, Bisexual and Transgender Patients http://ce5 4.citysoft.com/_data/n_0001/resources/live/GLMA%20guidelines%202006%20FIN AL.pdf

Removing the Barriers: Providing Culturally Competent Care to Lesbians and Women Who Partner with Women http://mautnerproject.org/programs_and_services/healthcare_provider_education/133.cfm

Appendix H: Evaluation Form

Making Us Visible Training Evaluation Form									
Location:									
Date:									
Please rate the following aspects of the training using the scale below: 1=strongly disagree 2= disagree 3=not sure 4=agree 5= strongly agr	ee								
1. The training met my expectations.	1	2	3	4	5				
2. I will be able to apply what I learned to my work.	1	2	3	4	5				
3. The training objectives were clearly identified and followed.				4	5				
4. The content was organized and easy to follow.	1	2	3	4	5				
5. The materials distributed were pertinent and useful.	1	2	3	4	5				
6. The presenter was knowledgeable.	1	2	3	4	5				
7. The presentation was interesting and useful.	1	2	3	4	5				
8. Group participation and interaction were encouraged.	1	2	3	4	5				
9. The group's questions and concerns were addressed.	1	2	3	4	5				
10. I would recommend this training to a friend or colleague.	1	2	3	4	5				
11. In terms of the work that I do, I found this training to be helpful.	1	2	3	4	5				
12. Overall, I think that this training is worthwhile.	1	2	3	4	5				
13. I feel I will be better able to serve lesbian and bisexual women as a result of this training	1	2	3	4	5				

14. Please list up to three things you liked about the training:

15. Please describe any changes that could be made to improve future trainings:

16. Additional comments:





