# Women, HIV & Stigma: A Toolkit for Creating Velcoming Spaces



WHAI.CA



# Toolkit content

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🔊 <u>www.whai.ca</u>

🔧 🛛 = A tool for you to use

#### WELCOME

1

3

- 1 Welcome to the WHAI toolkit
- 2 How to use this toolkit
- **3** Women & HIV/AIDS Initiative (WHAI)
- 5 How does WHAI work?

#### AN INTRODUCTION TO STIGMA

- 7 Stigma: an introduction
- 8 Stigma
- **9** Why do women experience so much HIV-related stigma?

#### TYPES OF STIGMA

- **11** Types of stigma
- 12 Institutional stigma
- 14 Activity: A group discussion about stigma
- 16 Social stigma
- 18 Internalized stigma
- **19** Stigma by association
- 21 Activity: The brick wall of stigma 🔧
- 23 Impacts of HIV-related stigma for women
- 24 Activity: Identifying stigma 🔧

#### CREATING WELCOMING SPACES

- 27 Creating welcoming spaces
- 29 Physical space
- **32** Organizational culture and atmosphere
- **33** Individual staff action
- **35** Language matters
- **36** Welcoming spaces for staff
- STRATEGIES TO CREATE WELCOMING SPACES
  - **39** Strategies to create welcoming spaces
  - **40** Aknowledging strength
  - 40 Ensuring representation
  - 41 Food

5

- 41 Centering Indigenous Experience
- 43 4 Steps to engaging women in welcoming spaces
- 44 Engagement
- 45 Questions
- 46 Facilitation
- 46 Space
- **47** Moving from planning to change making
- 49 Activity: Ladder of resiliency 🔧
- 51 Moving Forward
- 52 References

#### Cover Image

Lavender is a flower that calms the mind and evokes a strong and feminine energy.

# Velcome

SECTION

#### IN THIS SECTION

- 1 Welcome to the WHAI toolkit
- 2 How to use this toolkit
- **3** Women & HIV/AIDS Initiative (WHAI)
- 5 How does WHAI work?





WELCOME TO THE WHAI TOOLKIT

### This toolkit is part of a series created to assist community organizations and their staff to work with women<sup>\*</sup> in Ontario who are living with HIV and AIDS or who are facing systemic risk factors for HIV transmission. Let's get started. >>



\*Note: People have different comfort levels in language and have different language preferences. WHAI has worked to create these toolkits to be inclusive of all women, including cis and trans women, women with trans experience, as well as folks on the transfeminine spectrum. The terms 'woman' and 'women' are often used throughout the toolkits as umbrella terms, meant to encompass a wide range of identities.

# How to use this toolkit

#### SYMBOLS TO LOOK FOR

This toolkit has been divided into modules to help find:

#### OVERALL OBJECTIVES

What are we hoping to achieve with this toolkit?

- Support and foster knowledge of the issues faced by women living with HIV and AIDS
- Support and foster knowledge of systemic risk factors for HIV transmission
- Support and foster community organizations to connect and work with women living with HIV as well as those facing systemic risk factors for contracting HIV
- Provide practical tips, tools and strategies so that community organizations can build welcoming community spaces

#### HOW TO USE THIS TOOLKIT

Here are some helpful strategies to help you take advantage of this toolkit.

- This toolkit was designed to be completed in stages. Take your time and work through it at your own pace
- Consider completing it with others at your workplace or in your community
- This toolkit is a starting point and you or your organization may discover other learning points and areas for growth. Use the notes pages and let your local WHAI Coordinator know if you have any feedback



Tools designed to help you.



Helpful information and tips.



Thoughts and questions for further discussion.



Customize the toolkit with your own notes and ideas.

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Online resources Telephone services

# Women & HIV/AIDS Initiative (WHAI)

WHAT IS WHAI?



WHAI is a community response to HIV and AIDS among women in Ontario with a focus on the structural and societal factors that increase risk factors for HIV.

WHAI'S GOALS



Reduce HIV transmission among women.



Enhance local community capacity to address HIV and AIDS.



Create environments to support women and their HIV and AIDSrelated experiences.

#### WHAI'S OBJECTIVE

WHAI's objective is to strengthen the capacity of communities to support women living with and affected by HIV and AIDS.





WHAI works across the province of Ontario in 16 regions. To find a WHAI Coordinator near you, go to:

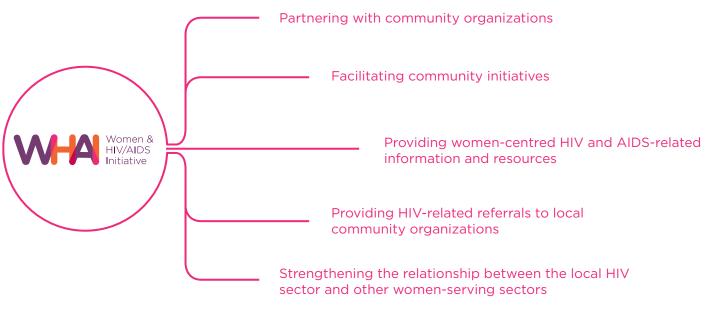
🔊 <u>www.whai.ca</u>

### How does WHAI work?

WHAI works primarily in partnership with other community organizations. This is because:

Research has shown that community organizations that women are already connected to and trust are often their primary point of accessing services such as sexual health care, mental health support, social connection, and information on HIV, even if they have not disclosed their HIV status.<sup>1</sup>

#### WHAI works toward building strong community change by:



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\*Note: Quotations are used throughout this toolkit to highlight the views and experiences of women. These quotations come from women with a range of identities and experiences. Some are African, Caribbean, Asian, Indigenous or Caucasian. Some are cis, some are trans, and some don't identify as either of these genders. Some of the quotes are from women who have been incarcerated, who are mothers, daughters, who sex work, use drugs or who have other identities. We have worked to include a range of voices and experiences; however, we have removed descriptors from the quotations to respect the complexities of women's identities. We cannot define a a woman by her race or an activity she has participated in. Instead, each is described as either a "worker" or a woman living with HIV, although even these identities can be complex and intersecting.

# An Introduction to Stigma

SECTION

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#### **IN THIS SECTION**

- 7 Stigma: an introduction
- 8 Stigma
- 9 Why do women experience so much HIV-related stigma?



# Stigma: an introduction

Our community organizations are an integral part of Ontario's response to HIV, particularly amongst women living with HIV or facing systemic risk for HIV acquisition. By creating what we're calling "welcoming spaces," community organizations have the capacity to build strong, inclusive communities that conquer stigma and discrimination. These are spaces where women feel valued for their experience and expertise without facing judgement, and where women actively participate in creating systemic social change. Not only is it ethical practice to create space where women living with HIV can participate without discrimination, it is also part of our organizational commitment to the Ontario Human Rights Code.<sup>2</sup>

Working to create and maintain welcoming spaces isn't always easy. Often, it requires looking critically at the way our organizations structure their physical space, as well as their culture and atmosphere. It also involves understanding the many ways women experience stigma and discrimination in our communities.

The first half of this toolkit is designed to explore women's experiences of stigma and discrimination in the following sections:

2 Stigma see page 8

Types of stigma see page 11

The second half provides tools to help create a welcoming space at your organization in the following sections:

Creating welcoming spaces see page 27

Strategies to create welcoming spaces see page 39



Note: Social determinants of health are the primary factors that shape the health of individuals – they are not medical treatments or lifestyle choices, but rather the living conditions that people experience.

Examples of social determinants of health include:

- poverty
- racism
- housing
- employment
- disability
- colonialism
- geographic location
- violence

#### FOR MORE INFORMATION

For tips and tools about the social determinants of health please see **Women & HIV in Ontario: An Introductory Toolkit** by WHAI.

<u>
 http://www.whai.ca/</u>
 <u>resources</u>



# Stigma

### [stig·ma]

Stigma, defined as negative attitudes, feelings or beliefs directed towards a person or group of people, has a significant impact on the lives of many women living with HIV, often acting as a pathway to unequal treatment, discrimination and marginalization.<sup>3,4,5</sup>

The process of stigma leading to discrimination and oppression is often sequential. For example, a belief (prejudice) about one person (stigma) is then applied to a group of people (a stereotype) and this impacts behaviours and actions towards those people (discrimination and oppression). In this way, discrimination and oppression are the enactment of stigma.<sup>6</sup> As such, stigma is an important area of work for community organizations in trying to address unequal treatment and oppression.<sup>5</sup>



#### **HIV STIGMA**

For many women living with HIV, experiences of stigma, discrimination and marginalization are common. HIV-related stigma is a negative belief about a person specifically related to either known or perceived HIV status.<sup>6</sup> This often leads to discriminatory behaviour. HIV stigma and discrimination often co-exist in multiple layers, intersecting with gender, sexual activity, race, income, physical and mental health, income and more.<sup>78</sup> Research has shown that this is particularly true for women. For example, the Ontario HIV Treatment Network (OHTN) Cohort Study showed that "women, and especially women of colour, score higher on measures of HIV-related stigma".<sup>9</sup> HIV-related stigma is an important area of work. Research has shown it has significant impacts on the health outcomes of people living with HIV and increases women's risk for contracting HIV.<sup>6</sup>

> "HIV stigma affects the quality of life, health opportunities received and sought, and psychological well-being of HIV positive women".<sup>10</sup>

> > - A support worker

As such, it is up to all of us to address stigma and create welcoming spaces where women who are living with HIV or facing systemic risk for contracting HIV are included. This is part of preventing HIV and improving the health outcomes of women living with HIV.<sup>5</sup>

#### WHY DO WOMEN EXPERIENCE SO MUCH HIV-RELATED STIGMA?

HIV has changed substantially in the past 20 years. People living with HIV and engaging in health care are living longer, are healthier, experience fewer side effects from medications, are able to have sex with less risk of transmission, and are able to consider pregnancy with little risk of transmission to the baby. Despite this progress, awareness about HIV has not been as quick to change, nor have judgements about women's behaviours that can lead to HIV.<sup>11,12</sup> Women are still dealing with judgement about how they contracted HIV and what it means to live with HIV.<sup>6,7,11,13</sup> This can often be a traumatizing experience for women. These factors are key drivers of HIVrelated stigma today, contributing to increased risk for women to contract HIV and reduced health outcomes for women living with HIV.



#### STIGMA THROUGH A MEDIA LENS

The media has the power to shift the landscape of HIVrelated stigma through the stories told or not told.

Reflect on the following questions:

- What are the dominant messages related to HIV embedded in media?
- 2. What faces do we attach to HIV when we think of media?
- How do these relate to our perceptions and understandings of HIV today?

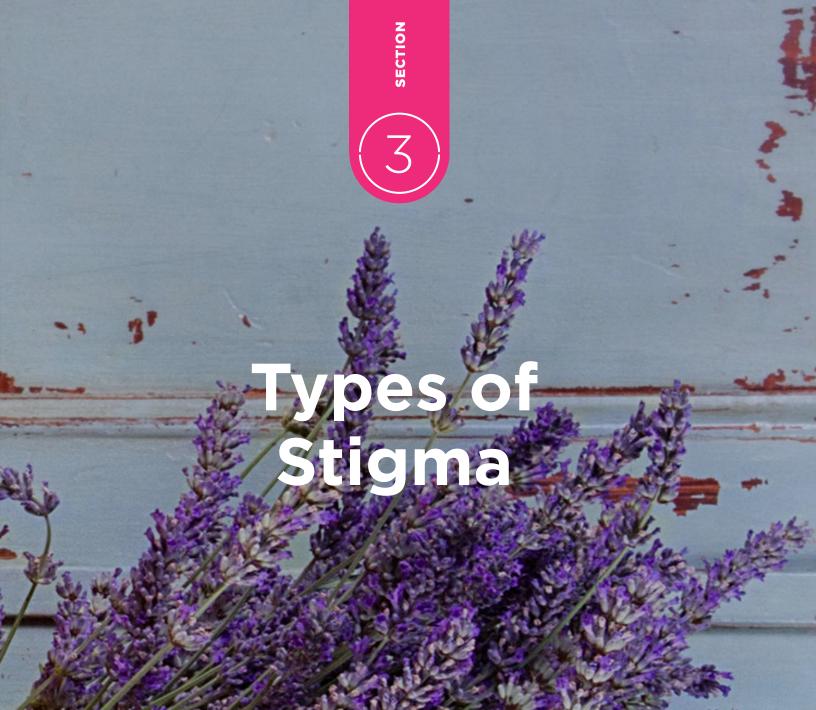


"Whoever controls the media, controls the mind."

- Jim Morrison

"A person who is living with HIV is a person like anyone else, and has the right to share love, the right to love, to be loved, to be sexual with someone who loves them."<sup>14</sup>

- A woman living with HIV



#### **IN THIS SECTION**

- 11 Types of stigma
- 12 Institutional stigma
- 14 🛛 Activity: A group discussion about stigma 🔧
- 16 Social stigma
- **18** Internalized stigma
- **19** Stigma by association
- 21 Activity: The brick wall of stigma 🔧
- 23 Impacts of HIV-related stigma for women
- 24 🛛 Activity: Identifying stigma 🔧

# Types of stigma

The next section will examine experiences of stigma through four main lenses, showing how each impacts women who are living with HIV or face systemic risk factors for HIV acquisition. Understanding each of these can assist in creating meaningful changes both with women who are living with HIV and those who are part of creating or perpetuating stigma.

#### FOUR TYPES OF STIGMA

The breakdown of stigma into these four areas is modelled by work done in harm reduction, disability rights, and LGBTQ communities.





Institutional stigma refers to stigma embedded in the policies, procedures and cultures of institutions such as governments, laws, and policies, including policies at community organizations. Often this form of stigma is unintentional; however, it has a negative impact on women living with HIV or facing systemic risk for HIV acquisition. Three examples of institutional stigma explored below are the health care system, the legal system, and the shelter system.



#### THE HEALTH CARE SYSTEM

Many women have positive experiences accessing health care, however, there is also research documenting the stigma and discrimination women experience. In some cases, women report being treated in a stigmatizing way by healthcare professionals because of their HIV status. Sometimes, this is rooted in a flawed fear of contracting HIV, and other times it is rooted in judgements about how a woman contracted HIV. It can be particularly true for women deemed "at risk" because of their community's association with HIV. One example is African, Caribbean and Black women who are often perceived to be carriers of HIV due to their race.<sup>7</sup> This perception of risk is based on colonialist power imbalances which disadvantage certain countries over others, rather than particular "risk" behaviours.

Pregnant and parenting people living with HIV can face this kind of stigma in a harsh way due to opinions about HIV transmission during pregnancy. While HIV treatment means the risk of transmission to a fetus or baby can be as low as 1%, judgement and perceptions about transmission have not changed as quickly.<sup>39</sup> "I was in crisis - I had to go see a doctor. When she came in she had three pairs of gloves on and yet it wasn't even a problem related to HIV! She kept her distance and could barely touch me"<sup>15</sup>

- A woman living with HIV

"When I had my baby I saw posters everywhere about the importance of breastfeeding. All the messages at the doctor's office told me I was a bad person if I didn't breastfeed. Then I had my obstetrician telling me that I wasn't allowed to breastfeed because of having HIV. People would sometimes even comment on the street if I was bottle feeding. They thought I was a negligent mother. Some of my friends and family who don't know I have HIV would judge me for bottle feeding"

- A woman living with HIV

#### HEALTH CARE CONTINUED...

According to research, women have also reported experiences where health care providers have:

- Made fatalistic comments
- Mocked them
- Blamed people living with HIV for their status
- Labelled people living with HIV
- Refused care to people living with HIV
- Physically abused patients living with HIV<sup>12</sup>

These are in addition to health care providers frequently sharing women's HIV status without permission.

While research shows that stigma amongst health care providers is decreasing<sup>16</sup>, it is important for community organizations to be thoughtful about women's experiences in the health care system, support women accessing health care, and educate healthcare providers about HIV and the impact of stigma.



#### THE LEGAL SYSTEM

The legal system idealistically aims to uphold ideas of justice and equity; however it can have negative impacts for women living with HIV. For example, while sexual assault laws have often failed to enact justice for women who report sexual assault, these same laws have been used against women for HIV non-disclosure, deeming them as sexual offenders and carrying a maximum sentence of life in prison. On paper, HIV non-disclosure laws are intended to 'protect' women from HIV; however, they have worked to criminalize women living with HIV, particularly women who have experienced intersecting life struggles such as poverty, family breakdown, violence and racism.<sup>17</sup> This is evident in statistics about who is charged. For example, as of 2016, 17 women living with HIV have been charged for not disclosing their HIV status. At least 5 of these were Indigenous women.<sup>18</sup>



#### THE SHELTER SYSTEM

Shelters are often spaces where women find safety from violence, poverty and marginalization, supporting women with their immediate and long-term needs; however, shelter policies can also contribute to institutional stigma.<sup>19,20</sup> For example, women are sometimes asked to give their medications to staff for safe keeping and regular dispensing. For many women living HIV, this requires them to disclose their HIV status, or creates fear that other women will find out about their HIV status. In addition, women who face risk factors for HIV also report difficulty in accessing shelters. For example, women who use drugs report experiencing stigma and discrimination when trying to access shelters.<sup>21</sup> As workers in community organizations and shelters, it is important for us to understand these experiences, to support women who are accessing shelters, and to engage people working at shelters to learn about institutional stigma and creating meaningful change.

### Activity: A group discussion about institutional stigma

#### INSTRUCTIONS

- Review the questions below with 2-5 people in your organization.
- Think about how your organization operates. Have each member record their thoughts and answers.
- Share and discuss each person's thoughts and ideas. See the sample answers on page 15.



WHAT ARE THREE EXAMPLES OF WAYS YOU CAN SUPPORT WOMEN TO NAVIGATE SYSTEMS THAT MAY BE STIGMATIZING?

- HOW DOES YOUR ORGANIZATION REDUCE/PREVENT INSTITUTIONAL STIGMA?
- IF YOUR ORGANIZATION DOESN'T HAVE POLICIES, PROCEDURES OR GUIDELINES TO HELP REDUCE INSTITUTIONAL STIGMA, HOW MIGHT YOU BRING THESE TO YOUR WORK?



ACTIVITY: A GROUP DISCUSSION ABOUT INSTITUTIONAL STIGMA

#### SAMPLE ANSWER SHEET

- The sample answers on this page correspond to the answers on the previous page.
- These answers are just a few samples, and we encourage your group to look at stigma from your personal and organizational experiences.



#### HOW MIGHT INSTITUTIONAL STIGMA IMPACT WOMEN?

Examples may include:	
 •	Isolation
•	Refusal to visit community organizations
•	Not taking medication
	A THE FILL FILL T

- Avoiding health care services
- Avoiding HIV testing
- Lack of self-care

WHAT ARE THREE EXAMPLES OF WAYS YOU CAN SUPPORT WOMEN TO NAVIGATE SYSTEMS THAT MAY BE STIGMATIZING?

- Examples may include:
  - Listen and validate women's experiences
  - Accompany women to appointments
  - Do educational workshops with other
    - community organizations involving
      - women who have lived experience

#### HOW DOES YOUR ORGANIZATION REDUCE/PREVENT INSTITUTIONAL STIGMA?

IF YOUR ORGANIZATION DOESN'T HAVE POLICIES, PROCEDURES OR GUIDELINES TO HELP REDUCE INSTITUTIONAL STIGMA, HOW MIGHT YOU BRING THESE TO YOUR WORK?

- Examples may include:
  - HIV training
- Anti-oppression anti-racism training
- HIV disclosure policy
- Gender neutral washrooms
- Community feedback processes

Examples may include:

- Contacting your local WHAI Coordinator
- Discussing at a team meeting
- Bringing samples to work from other agencies



Social stigma refers to stigma embedded in social relationships and interactions. Our social relationships are often the places where we find important sources of strength and belonging. However, these can also be a place where we experience judgement, shame and exclusion. In some cases, social stigma is so prevalent that it can be also considered institutional stigma. Sometimes social stigma is directly related to HIV status, and in other cases it is created by beliefs and judgements about behaviours that increase risk for contracting HIV. This section outlines various examples of social stigma.



#### **FAMILY & FRIENDS**

Women's relationships with friends and family are often impacted significantly by disclosing their HIV status. Women sometimes fear judgement or rejection from these important supports.

> "I've had HIV for five years now. My parents don't know and I'm scared to tell them because my mom will have a heart attack."<sup>22</sup>

> > - A woman living with HIV

"You think they're close friends, you decide to open up to them and say 'I have HIV'. But then they don't want anything to do with you anymore. They stop calling, they stop coming over"<sup>22</sup>

- A woman living with HIV



#### SEXUALITY

Not all sexual behaviours are embraced by society. Some women may have one partner or many partners, and some women may engage in a variety of sexual activities. Fear and judgement about sexual activities can impact how women are treated in social relationships and consequently result in discriminatory treatment.

> "Because it's sexually transmitted people look at it like you're dirty, you're not clean, bringing it on yourself"<sup>22</sup>

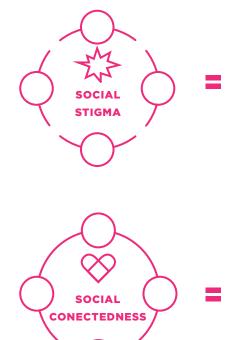
> > - A woman living with HIV

People assume "you weren't protecting yourself...it could have been a broken condom from a long-term boyfriend. And all of a sudden everyone treats you like dirt"<sup>23</sup>

- A woman living with HIV

Social stigma, whether related to sexuality, bonds with family, friends or other relationships, can have a significant impact on women, contributing to shame, withdrawal and negative health outcomes.<sup>24</sup>

Conversely, strong, supportive social connections are shown to positively impact women's health.<sup>25</sup> It is important that our community organizations understand social stigma, and work to build inclusive, supportive spaces.



#### SHAME WITHDRAWL NEGATIVE HEALTH OUTCOMES

**POSITIVE HEALTH OUTCOMES** 



Internalized stigma (also called self-stigma) related to HIV, refers to a "negative self-concept and sense of shame and blame associated with being HIV-positive."<sup>15,26</sup> Women experiencing internalized or self stigma may have internalized the negative messaging they have experienced through institutional, social stigma, and stigma by association. For many, the experience of internalized stigma leads to shame which has been shown to result in withdrawal, avoidance, a negative attitude about oneself, and the perpetuation of negative relationships with others.<sup>27</sup> Internalized stigma is also related to perceived HIV stigma, meaning when someone believes people are judging them.

Rates of depression among HIV-positive women from African, Caribbean and Black communities in Ontario are five times higher than other women across Canada.<sup>6</sup> Often experiences of internalized stigma translate into feelings of worthlessness, and a sense of powerlessness to create change in one's life. In many cases, this internalized stigma contributes to worse health outcomes for women living with HIV, and increased risk behaviours for women who already face systemic risk factors for contracting HIV.

Research has shown that internalized stigma is strongly correlated to risk for depression, decreased self-esteem and self-efficacy, feelings of hopelessness, trauma and psychological distress.<sup>13</sup> Further, depression has shown to be more intense and significant for those experiencing multiple forms of stigma, including racism and sexism. Ultimately, understanding internalized stigma is a critical component to working with women who are living with HIV or facing systemic risk for HIV acquisition. It helps provide insight into why women we're working with may stay in unhealthy relationships, are avoidant or even destructive about services in the community, and why women are sometimes defined as "hard to serve."



Rates of depression among HIV-positive women from African, Caribbean, and Black communities in Ontario are five times higher than women who are not living with HIV.<sup>40</sup>

"The first thing you think about is how yucky you are, and then some people think suicide. I know a few people that have killed themselves"<sup>28</sup>

- A woman living with HIV

"It's not HIV that kills you. It's the stigma and discrimination from society, the rejection that makes people go into depression and stop taking their medication, stop taking care of their health. That is when they get sick."<sup>14</sup>

- A woman living with HIV

#### **DISCUSSION QUESTIONS**

- 1. How might internalized stigma impact a woman's capacity to get an HIV test?
- 2. How might internalized stigma impact a woman's capacity to engage in medical care?
- 3. How might internalized stigma impact a woman's relationships with her family/friends?
- 4. How might internalized stigma impact a woman's interaction with a support worker?



Stigma by association, also referred to as courtesy stigma or symbolic stigma, refers to stigma related to a relationship with someone who is affected by stigma. This type of stigma is under-researched, however, it impacts people who are living with HIV, their supports, and people who face systemic risk factors for acquiring HIV.<sup>5,29</sup> One example of stigma by association is when people experience judgement because of their relationship with a group perceived to be carriers of HIV. This is true for African, Caribbean and Black women as well as women who sex work and women who inject drugs. All of these groups face judgement about their behaviours and assumed HIV risk despite the use of prevention practices.

#### **STIGMA BY ASSOCIATION IN NUMBERS**

In a Canadian longitudinal survey looking at attitudes and knowledge about HIV:<sup>32</sup>



of participants reported they would be uncomfortable working in an office with someone living with HIV.



would be uncomfortable if their child was attending a school where one of the students was known to be living with HIV.





would be uncomfortable with a close friend or family member dating someone living with HIV.

#### STIGMA BY ASSOCIATION CONTINUED...

Experiences of stigma by association can have negative impacts on people's social relationships and support networks while also influencing people's willingness to get an HIV test, take treatment, disclose their HIV status, or access HIV-related supports.

"I'm dying of sadness, having to hide this"<sup>22</sup> - A woman living with HIV

> "Women often won't pick up harm reduction supplies here because they fear being associated with people who use drugs. They fear someone will judge them as a parent, even though accessing the service could prevent HIV. They also fear people will report them to CAS [Children's Aid Society] for being a bad parent. Women have to be so careful and secretive, and it often means they are more at risk."

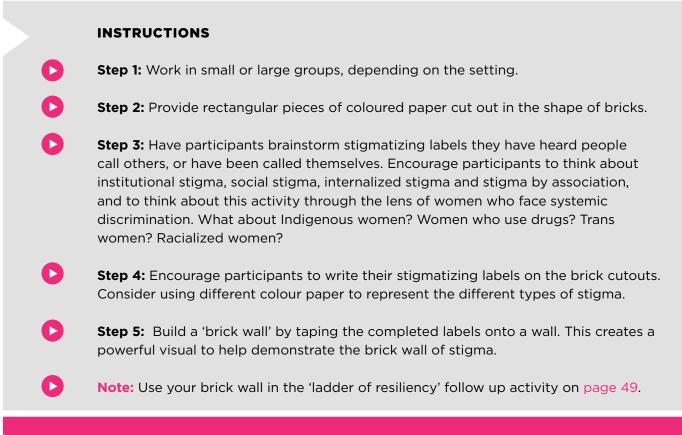
- A harm reduction worker

Understanding stigma by association can inform how we structure programs in our communities. We may choose to create programs that don't explicitly state HIV in the title or that are located in non-HIV service organizations. It can also inform how we work with women who are living with HIV or face systemic risk factors for contracting HIV. We may choose to offer harm reduction supplies in private spaces as well as public spaces. Ultimately, these practices can help reduce barriers and enhance the work we do in communities.



# Activity: The brick wall of stigma

This activity is appropriate for people who work in community organizations, women with lived experience or combined groups. It is designed to provide a visual illustration of how people can face intersecting forms of stigma, and how stigma can create a "brick wall" preventing women from moving forward.



#### TAKE A MOMENT TO REFLECT

Have participants share the ideas they came up with and reflect on what they see.

- Is anything missing?
- Have you experienced/worked with anyone who has faced many of these?
- How does it feel to look at a wall of these stigmatizing labels?
- What might the impact be of facing multiple labels?



ACTIVITY: BRICK WALL OF STIGMA



#### FACILITATOR NOTES

Encourage participants to take care of themselves when they do this activity. It can be difficult to think about all the layers of stigma & discrimination people face."?

Here's how to make your own "brick wall of stigma."





**Step 1** Assemble a group

**Step 2** Create brick cutouts using coloured paper



**Step 3** Brainstorm stigmatizing labels



**Step 4** Write stigmatizing labels on bricks



#### Step 4

Build your brick wall by taping paper bricks onto a wall

# Impacts of HIV-related stigma for women

HIV-related stigma can have significant impacts on women's likelihood to acquire HIV, get tested for HIV, engage in HIV treatment, stay on treatment, and have successful health outcomes. It also impacts women's capacity to socialize, engage in healthy relationships, and increases the likelihood of developing mental health issues such as depression and anxiety. In fact, HIV-related stigma is statistically shown to be associated with increased rates of depression.<sup>26</sup>

#### WHAT IS INTERSECTIONALITY?

When learning about the impact of various forms of stigma on women's lives, it is important to understand how stigma interacts with structural factors such as racism, misogyny, classism, and transphobia among others. This concept is referred to as intersectionality and it describes how these structural factors are connected. When people's lives are subject to several of these categorizations, multiple and overlapping oppressions create greater barriers to achieving positive health outcomes.<sup>47</sup> As is shown throughout this toolkit, HIV disproportionately impacts women who experience several forms of marginalization. For example, research done in Ontario found that, among women living with HIV, there was an interdependent relationship between HIV-related stigma and the multiple oppressions of racism, sexism, and transphobia.<sup>7</sup> This relationship results in unique and complex outcomes for women of different social identities. As workers, it is important to acknowledge the ways stigma impacts women differently across identities and at all levels. It's important to remember that there is no "one size fits all" approach to addressing the impact of stigma on women's lives.

#### THE PATH OF STIGMA

Stigma can lead some women down a path where shame prevents them from taking preventative measures or accessing treatment for HIV. To illustrate this see the following example:

Judgement about a woman's sexual activities or drug use are often perceived negatively, creating shame. In turn, women are likely to hide these practices, or face judgement and even criminalization based on these practices. As a result, some women may have reduced access to preventative measures and experience increased risk taking behaviours.



# Activity: Identifying stigma

#### INSTRUCTIONS

When working with women who have HIV, it's important to understand different types of stigma they may face. Review the various types of stigma, and example situations below.

Match the type of stigma to the corresponding situation(s) by drawing a line between them.

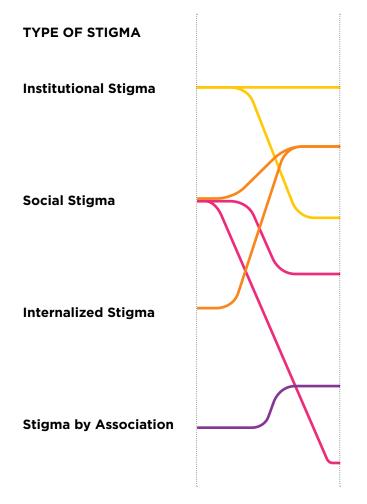
**Note:** Different types of stigma overlap and interconnect. There may be more than one answer for each.

TYPE OF STIGMA	EXAMPLE SITUATION
Institutional Stigma	An organizational policy to share people's HIV status amongst team members.
Social Stigma	"Dating is hard. I haven't had a date in so many years. Disclosing is such a difficult thing and every time I fear being rejected." - <i>A woman living with HIV</i> An organizational policy to use gloves if we are aware of someone's HIV status.
Internalized Stigma	"Everybody in the community, they know I'm HIV-positive and they talk bad about me. You know, they even call me names. They don't know me, they don't know anything about me, but still, because they found I'm HIV-positive, they think I'm a bitch lady." - <i>A woman living with HIV</i> <sup>33</sup>
Stigma by Association	"Women don't want to go to our agency because they don't want to be associated with HIV." - <i>Staff from an HIV Service Organization</i>
	"You're labelled as a pest of society because you're infected." - <i>A woman living with HIV</i> <sup>22</sup>



#### INSTRUCTIONS

Review the correct matches below and continue the discussion below.



#### **EXAMPLE SITUATION**

An organizational policy to share people's HIV status amongst team members.

"Dating is hard. I haven't had a date in so many years. Disclosing is such a difficult thing and every time I fear being rejected." - *A woman living with HIV* 

An organizational policy to use gloves if we are aware of someone's HIV status.

"Everybody in the community, they know I'm HIV-positive and they talk bad about me. You know, they even call me names. They don't know me, they don't know anything about me, but still, because they found I'm HIV-positive, they think I'm a bitch lady." - *A woman living with HIV*<sup>33</sup>

"Women don't want to go to our agency because they don't want to be associated with HIV." - *Staff from an HIV Service Organization* 

"You're labelled as a pest of society because you're infected." - A woman living with  $HIV^{22}$ 

#### **DISCUSSION QUESTIONS**

- How did your matches compare to the matches provided?
- Have you ever faced situations like this in your work with women with HIV?
- How can your organization start to reduce the impact of stigma in your workplace?

# Creating welcoming spaces

SECTION

#### IN THIS SECTION

- 27 Creating welcoming spaces
- 29 Physical space
- 32 Organizational culture and atmosphere
- **33** Individual staff action
- **35** Language matters
- **36** Welcoming spaces for staff

# Creating welcoming spaces

#### INTRODUCTION

Now that we have explored some of the many ways women experience stigma, discrimination and marginalization, and how these experiences can impact women's health outcomes, it is important to find ways to reduce these experiences and build welcoming, inclusive community spaces. As workers in community organizations, we are in important positions to do this work. This section will explore:

- What a welcoming space is, including the physical space, the organizational culture, and the role of individual staff
- 2 Strategies to create welcoming spaces in our community organizations

#### WHAT IS A WELCOMING SPACE?

'Welcoming spaces' is a phrase referring to spaces that help connect people and create a sense of community. Many agencies are oriented to deliver services by professionals in an expert role. Innate in this dynamic is a relationship of "professional" and "client" creating a sense of need, vulnerability and disempowerment rather than acknowledging the strength, skill and expertise of women. Welcoming spaces seek to shift this dynamic and build inclusive communities. These are places where women can go to foster connections with each other, share resources and information and have a sense of belonging. A welcoming space can reduce a woman's feeling of isolation, enhance the capacity of women to build health and wellbeing, and focus on the strengths of women's differences and diversity. In many cases, welcoming spaces can serve as a haven from stigmatization and discrimination.



Note: Many sectors have done amazing work to create safe and welcoming spaces including LGBTQ, violence against women, trauma-informed, and Indigenous sectors. In addition, in 1997 the AIDS Committee of Ottawa developed a seminal resource on making space work for communities living with HIV.<sup>34</sup> This toolkit has drawn on much of this great work.

#### FOR MORE INFORMATION

Check out the **Women and HIV in Ontario: An Introductory Toolkit** resource to find helpful ways to build these skills.

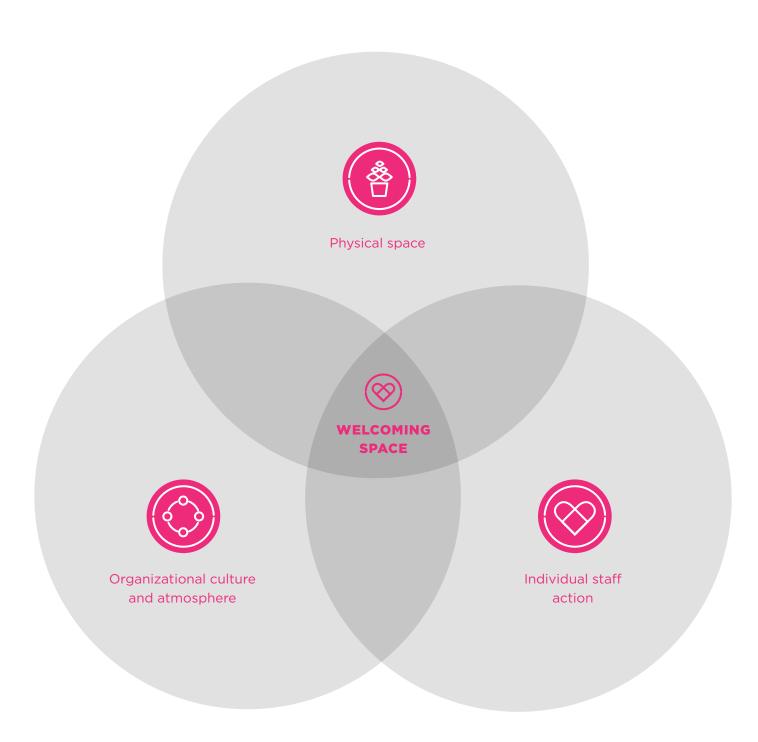
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Creating welcoming spaces involves making a commitment to address the factors that make women vulnerable to HIV, becoming informed about HIV prevention, being able to provide accessible HIV resources, being able to make trusted referrals, and committing to reduce HIV stigma and discrimination.

#### COMPONENTS OF A WELCOMING SPACE

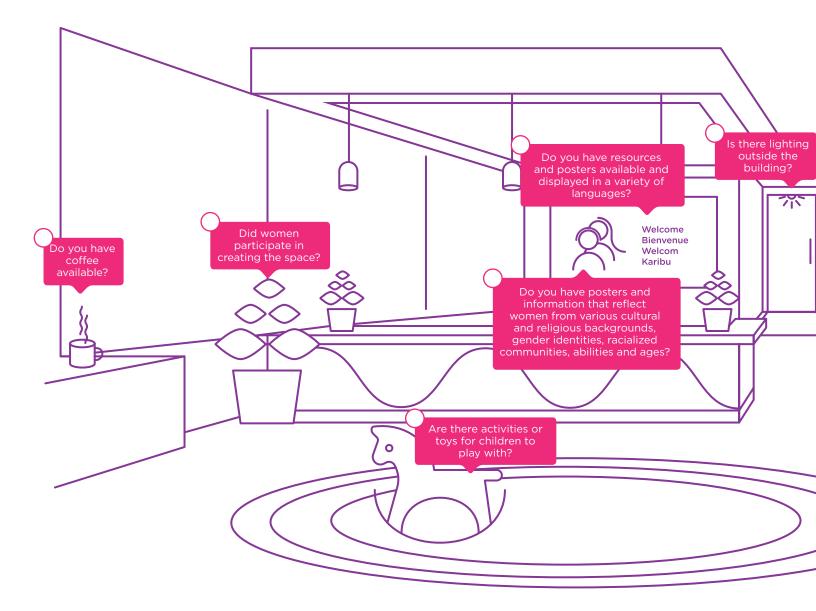
We are working from a model where a welcoming space considers three areas:





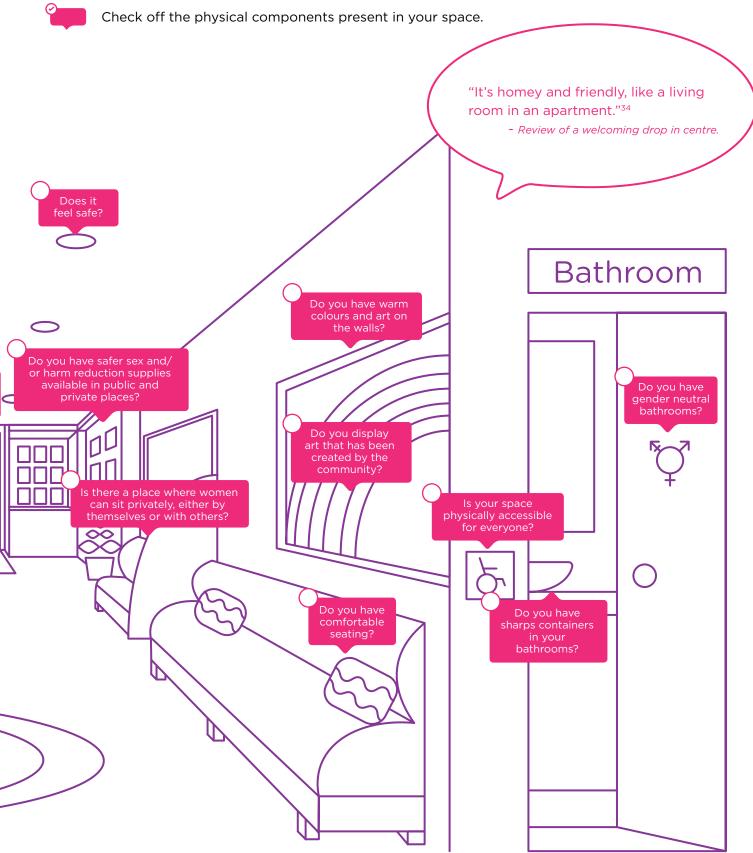
One aspect of a welcoming space is the physical environment. The physical space at your organization is important for a few reasons:

- it sets the tone for the impression women will have of your organization
- the physical organization of space directs the flow of people, encouraging engagement
- the way space is designed has an impact on how women will experience your organization and develop a sense of connection



#### WHEN YOU LOOK AROUND YOUR ORGANIZATION, WHAT DO YOU SEE?

These are just some of the physical components of space that can affect how welcoming it is to women.



30 | WHAI Toolkit

#### PHYSICAL SPACE CONTINUED...

Research has shown that physical environments, when well designed around welcoming concepts, lead to higher rates of engagement and satisfaction.<sup>35</sup> This means that welcoming spaces not only attract more women to come and participate in the organization, but that health outcomes for women can improve as well. There is also a strong relationship between how safe women feel and their use of the space. Included below are a set of guiding questions which have been adapted from work UN Women has done on making spaces physically safer to access:<sup>36</sup>

- ) Is there easy access to and from your organization (i.e. public transportation)?
- Is there easy movement within your organization?
- ) Is there lighting so that women can see and be seen?
- Are there easy-to-read signs to help women find their way?
- Does your organization maintain clear, well-kept paths where people can easily see each other?
- ) Is there general visibility of the entire space, free from hiding places where a person could wait unseen?
- Does your organization include mixed uses places to hangout, walk, eat, etc. for diverse user groups at different times of day?
- Does your organization have provisions for young children and the elderly (because women are often caretakers), e.g. wide hallways for strollers, wheelchairs and walkers, and childcare?



If women who may have experienced trauma are accessing your community organization, these are also important considerations from a trauma-informed perspective.



#### FUNDING YOUR WELCOMING SPACE

We recognize that when talking about examining and making changes to your organization's physical space, concerns can often arise about cost and feasibility. There are several ways to make changes to your physical environment that are low to no cost and can engage women in the process.

These are explored on page 39

#### FOR MORE INFORMATION

You can refer to the **Women** and **HIV in Ontario: An Introductory Toolkit** resource for a checklist of other physical components of a welcoming space.

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# Organizational culture and atmosphere

Organizational culture and atmosphere also play an important role in creating welcoming spaces.<sup>34</sup> Consider the ways in which the structure and systems within your organization create a culture and atmosphere that normatively governs how people exist and operate in that space and how that can affect women living with and facing systemic risks for HIV.



#### TRAUMA INFORMED WORK

Many women have experienced traumatizing events in their lives. Given the intersecting stigma women living with HIV and women having systemic risk for HIV face, a trauma-informed approach is particularly important to create a welcoming space.

#### **ORGANIZATIONAL CULTURE & ATMOSPHERE CHECKLIST**

- Are the staff committed to working from a feminist, antiracist, anti-oppression perspective?
- Do hiring practices foster representation from important communities such as Indigenous women and African, Caribbean and Black women?
- Does your organization have policies and procedures that will ensure women are safe and included?
- Do you have policies about disclosure and confidentiality?
- Have you reviewed your intake form from the perspective of people who come to your organization? Does it respect people's experience, privacy and identity? Is it inclusive of genders? Does it ask unnecessary or overly personal questions? Does it foster a welcoming space?
- Do you operate from a strong harm reduction framework?
  - Are staff familiar with trauma-informed work and strategies?
- Are the staff open to having non-judgemental conversations with women as well as with co-workers about HIV and sexual health?

#### FOR MORE INFORMATION

Changes to organizational culture can take time. Your local WHAI coordinator can work with you to help identify areas where organizational change is needed and possible.

Find a WHAI coordinator near you:

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Having these systems-level discussions isn't necessarily easy. Even when the policies exist, there are challenges in day-to-day practices that can negatively impact the women coming through your doors.

Having inclusive policies and making a commitment to working within a welcoming organizational culture makes your organization more appealing to women.<sup>37</sup> These policies are the foundation of how people interact with each other in your space.

# Individual staff actions

As workers in community agencies, body language and what we say can impact the experience that women have when they come through the door. Being kind, warm, and treating people with patience and dignity can make a world of difference for women living with HIV, regardless of whether you know someone's status or not. Individual staff actions can be an important pathway to building trust and in creating space for women to share their experiences and expertise. These strategies also foster a traumainformed approach in your community organization.

#### INDIVIDUAL STAFF ACTION CHECKLIST

Take time to evaluate your own capacity to work with women who are living with HIV or facing systemic risk for HIV acquisition.

- Do you feel comfortable in your ability to work from an informed place?
- Are you prepared to listen and embrace women's experience and expertise as part of building inclusive communities and creating community change?
- Are you able to ask non-judgemental questions when you don't understand something?
- Are you able to work with women to address the stigma and discrimination they may be experiencing as a result of HIV?

This means challenging our own ideas of professionalism and expertise as a "service provider" compared to providing support and working with women as experts of their own lives. Ultimately, this means switching the dynamic of who has the expert knowledge, and shifting away from "client" to community member. It also means shifting away from the notion of people as broken and in need of expert help.

These individual level assessments can be difficult but it is important for us to work together to create systemic change, and transform women's experiences in our community organizations.

"When people come to our organization, we greet each and every person. We want to know everyone, and to create a warm space. And we want people to feel comfortable to talk to us and tell us about what's happening in their life and in the community. This helps us to be aware of what areas of work we need to be doing in our community. We divide our staff time so that there is always someone responsible for greeting people coming in and having a conversation."

> - A support worker at an HIV service organization in Ontario



#### **BODY LANGUAGE**

Body language can make a significant difference in a woman's experience with us. Consider how you approach people who come in to your community organization. Speaking gently and calmly, giving physical space, standing slightly to the side, and having relaxed limbs can all help create a welcoming space. Actions such as approaching quickly, speaking loudly or aggressively, standing too close and crossing your arms can all feel intimidating and even confrontational. Keep in mind that body language can differ between cultures and social groups.



#### WHAT WE SAY

Words carry power and have the ability to affect the way we see ourselves, others, and the world around us. Language has the ability to empower and strengthen relationships with women accessing services. However, inappropriate and disrespectful language can further isolate and contribute to the stigma experienced by marginalized communities. Inclusive and respectful language is an integral part of ensuring a safe and welcoming space.

When working with women it is important to use "people first" language.<sup>38</sup> This means that the person is always put before their diagnosis and is not defined by specific experiences. For example, when we say 'person living with HIV', or 'person who uses drugs' we place the person first and ensure they are not limited to their HIV status or experience using drugs. By defining people first, we affirm and emphasize our shared humanity, and acknowledge that identities are nuanced, evolving, and lavered.38



#### A WARM WELCOME

To help create a welcoming environment in your organization, instead of asking "can I help you?" when someone enters your organization, say a warm hello and let them know where the coffee or drinks are. This will allow people to get comfortable with the space before they actively engage.<sup>34</sup> It can also be a warm way of engaging people who are visibly distressed or upset while offering support.



"Some campaigns use sex positive language that can be seen as in your face or too explicit in certain communities where it is difficult to talk about sex. These campaigns can be important to build sex positivity and starting important conversations about sex; however, they can also be seen as offensive in some communities. It is important for us to be thoughtful about language and how it impacts various groups when we create messaging."

- A support worker at an HIV service organization in Ontario

#### LANGUAGE MATTERS

Use the table below to explore how to speak about HIV with sensitivity.

	USE	(?) WHY
AIDS patient, HIV- infected	Living with HIV	It is important to put the person before their HIV status. <sup>39</sup>
Mother-to-child transmission	Vertical or perinatal transmission	The term mother-to-child transmission is based on cis-normative gender expectations and assumes the birth parent will be the "mother." It also excludes the possibility of transmission prior to birth, where the term fetus is used instead of child or baby. It also perpetuates "mother blaming." <sup>39</sup>
HIV/AIDS	HIV or AIDS	HIV is a chronic illness - most people living with HIV do not have AIDS. <sup>39</sup> It is important for us to be aware of what HIV and AIDS mean, and use the correct language for what we are talking about.
Coloured people	People of colour, racialized people	Using people first language is important. The term "racialized" is helpful because it identifies groups who experience differential economic, political, social and psychological treatment based solely on the racial and or ethnic group they identify with.
Prostitute, prostitution	Sex Work, women who trade sex, women who sell sexual services, sex working women	Prostitution/prostitute is a deeply-rooted negative and legalistic term. <sup>40</sup> It is also important to use people first language here. Women who sex work often get labelled by their work rather than recognizing them as people.
Drug user, addict, drug abuser, junkie, crack whore	Person who uses drugs / woman who uses drugs	It is important to put the person first and ensure they are not defined by drug-related experiences.
Clean	Sober	The use of the term 'clean' is rooted in blood drug screening; however, it carries a message about people who use drugs being unclean or dirty which is harmful.

#### THREE PRACTICAL TIPS FOR USING INCLUSIVE LANGUAGE:



#### **Educate yourself**

It is your responsibility to stay up to date on anti-oppressive language and practices. Consider presentations from other community partners, have conversations with colleagues, and access the abundant list of online resources available to you.



#### Use plain language

Be aware of varying literacy levels and primary languages spoken, avoid 'jargon' that may be inaccessible, and make sure your community organization is connected with interpretation services. Where possible, have resources printed in various languages.



Listen to women and use the terminology they use in defining their own sexuality, gender and family relationships

Women are experts of their own lives and know what terms they prefer to use to express themselves (be mindful that in some situations women may use terminology that is not acceptable for individuals not identifying within a specific community to use).

#### WELCOMING SPACES FOR STAFF

In community organizations that provide social programs and supports, the morale and happiness of staff is directly linked to the quality of programs we can provide. At the foundational level, we are producing a human product (support, community). When workers feel valued, comfortable and happy at work, the quality of their "product" will improve. When building welcoming spaces, it is important to also consider the needs, wants and strengths of our staff teams.

Ways to do this include asking staff what would make them feel more comfortable at work, asking staff to participate in decision making, allowing staff to personalize their workspace or bring pets to work occasionally (permitting there are no health issues), encouraging collaboration, promoting work/life balance, and creating a culture where staff feel valued for their efforts.




# Strategies to create welcoming

Dace

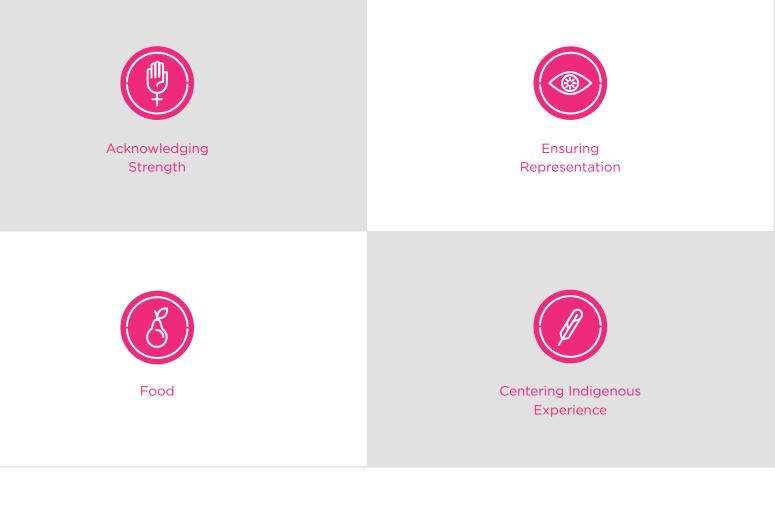
SECTION

#### IN THIS SECTION

- **39** Strategies to create welcoming spaces
- 40 Acknowledging strength
- **40** Ensuring representation
- 41 Food
- 41 Centering Indigenous Experience
- **43** 4 Steps to engaging women in welcoming spaces
- 44 Engagement
- **45** Questions
- 46 Facilitation
- 46 Space
- **47** Moving from planning to change making
- **49** Ladder of resiliency
- 51 Moving forward

### Strategies to create welcoming spaces

Now that we have established what welcoming spaces are, the following section provides practical strategies to build welcoming spaces.



### Learn more >>

### Acknowledging strength

Now that you're comfortable with the framework of welcoming spaces, how do you actually work to improve your own space? The first step is acknowledging that women in your community are the experts. It is more impactful to engage women from a place of strength and to explore what they would like and what they can offer to the process than to work from a place of need and try to "fix" or "solve" women's problems for them.

#### **ACTION CHECKLIST**

Allow women to share their ideas, rather than try to fix or solve women's problems.



People feel more connected when they can see people they identify with. If your agency aims to work with women living with HIV, it is important to have staff, volunteers, managers and board members who reflect that group of women. It is important to ensure there are meaningful ways to be involved. The GIPA and MIPA (greater and meaningful involvement of people living with HIV) principles aim to put people living with HIV at the center. Since approximately 50% of new HIV cases in Ontario amongst women are from African, Caribbean and Black Communities,<sup>31</sup> it is important to have people from those communities working, volunteering and visiting your organization. This can also help with some of the culture shock for people who are new to Canada. The experience of seeing someone who looks like you can help to reduce some of the isolation and trauma from the experience. Displaying advertisements and posters that include women from diverse backgrounds, including African, Caribbean and Black women, trans women, Indigenous women, and other women you serve is also helpful.

#### ACTION CHECKLIST

Have staff, volunteers, managers, and board members be representative of women living with and facing systemic risks for HIV in your community.

Display art, posters and materials that women in your community can see themselves reflected in.

**50%** of new HIV cases in Ontario amongst women are from African, Caribbean and Black communities.<sup>31</sup>



People congregate around food. It brings people together and helps build community. Offering food during programs or group sessions can assist in bringing people in, engaging women, and helping build community when possible. This is particularly true of warm, homemade food rather than donuts, pizza, or cold food. Food is an extension of hospitality that serves to welcome people into a space and a community. It can also assist in bringing in women who are living in poverty and struggling to afford nutritious food. Hot food can be more expensive; however it can also be an opportunity to prepare food together which is more affordable. If the cost is prohibitive, offering tea or coffee is also a gesture of hospitality.

#### **ACTION CHECKLIST**

If possible, provide warm or homemade food at programs or group sessions

Provide nutritious options including fruit, and baked goods

Consider cooking together as part of the program

At a minimum, try to provide a warm cup of tea or coffee

# Centering Indigenous experience

Canada's history of colonialism and the continued impact of residential schools has created a system where Indigenous communities experience social determinants of health that contribute to negative health outcomes – including higher rates of HIV among Indigenous women.

In 2015, the Truth and Reconciliation Commission of Canada released their report which was created from six years of work with Indigenous Canadians who witnessed and/or survived the residential school system. The report emphasizes the need to actively close the gaps between Indigenous and non-Indigenous Canadians. In the creation of welcoming spaces, we can include this incredibly important work by considering Indigenous culture, knowledge, concepts and how they can be applied to our organizations.<sup>41</sup>

In the context of welcoming spaces, you can help to build space for Indigenous communities through a few key actions:



#### **SEEKING TRUTH & UNDERSTANDING**

Beginning reconciliation work and creating a welcoming space for Indigenous women in your community may not be easy. A good first step is to familiarize yourself with the continued impact of colonialism and the residential school system in Canada on Indigenous women. The findings from the Truth and Reconciliation Commission of Canada demonstrate that Canadian institutional/government practices result in the health status of Indigenous women falling well below that of non-Indigenous Canadians.<sup>42</sup> For example, Indigenous women experience significantly higher rates of intimate partner violence, assault, and are more likely to be killed than non-Indigenous women in Ontario.<sup>43</sup> In the context of HIV, Indigenous women are more likely to contract HIV than non-Indigenous women, representing almost 50% of new diagnoses among Indigenous people in Ontario (2015).<sup>44</sup> By seeking to understand the social, cultural and historical contexts that surround the health issues of Indigenous women, our community organizations will be better positioned to work with Indigenous communities across Ontario.



#### **BE THOUGHTFUL ABOUT INDIGENOUS PRACTICES**

The creation of welcoming spaces should be a participatory process. As such, it is a way of including Indigenous women in the process of planning and implementing this work. Being cognizant of Indigenous knowledge systems and traditions such as smudging, storytelling and oral histories, cultural interpretation and traditional health models will serve to help build inclusionary practices.<sup>42</sup> See the 4 steps to creating participatory welcoming spaces section on page 43. for ideas and strategies on how to include Indigenous and non-Indigenous women in the development of spaces.

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#### INDIGENOUS RESOURCES ACTION CHECKLIST

Several organizations have created recommendations and guiding principles for working from an Indigenous perspective, some of which may be helpful to you and your organization. All of these resources can help guide the work. Your local WHAI Coordinator can also assist with connecting you to appropriate partners and resources.

#### The Ontario Aboriginal HIV/ AIDS Strategy (Oahas)

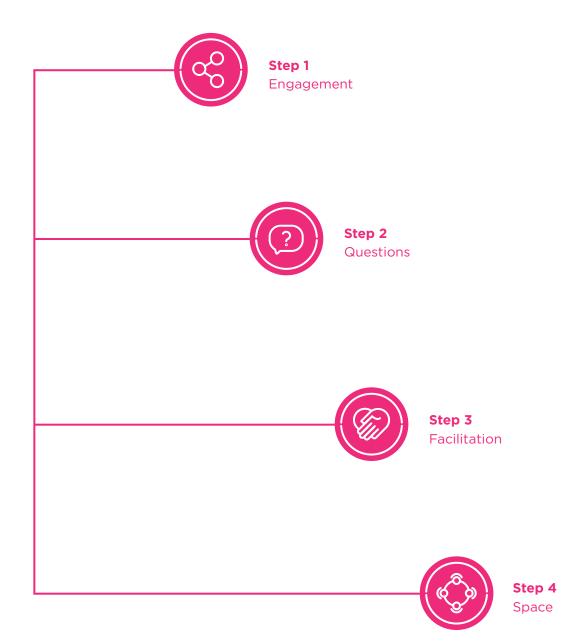
- 🔊 <u>www.oahas.org</u>
  - The Native Women's Association of Canada
- 🔊 <u>www.nwac.ca</u>
  - The Truth and Reconciliation Report
- <u>A http://www.trc.ca/</u> <u>websites/trcinstitution/</u> <u>index.php?p=890</u>

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### 4 Steps to creating participatory welcoming spaces

Creating productive and inclusive dialogues within your space is an important way to build trust, inclusivity and a culture of strength and empowerment. Consider using these four steps to start help spark a dialogue.





Women are often more likely to participate in community organizations when they are valued for their important contributions rather than being treated as passive recipients in need of services.<sup>45</sup> One way to start this process is to hold meetings, gatherings or focus groups with women who access your organization and women in your community. Include women who frequent your organization, key "community champions," and even volunteers.<sup>34</sup> It is also important to consider inviting some of the women you may have a more challenging relationship with. For example, are there women who have been deemed "problematic" at your organization? Are there women who have expressed frustrations? Having a diverse group of women participating is an important part of creating inclusive, welcoming spaces. In these cases it is also important to have strong facilitation skills and be able to build respect into the conversation from all participants.





Once you've planned your groups, ask questions to assess the strengths and needs of your space. Questions create space for new ideas to emerge and engage women in the process of creating change. Ask questions that are open-ended and build engagement.

#### QUESTIONS TO ASK YOURSELF

- How are women feeling and experiencing your organization?
- What are the key things that could improve?
- What in your space is working really well?
- Are there other community agencies that women prefer going to and why?
- What is the commitment that brought you to participate here?
- Why is this valuable to you?
- What gifts or skills do you have to bring to this process?







In addition to questions, it is important to consider the context and how people engage with each other. This means you need strong facilitation skills, and to be thoughtful about the questions you're asking and how you're listening and responding to the answers.

- Are you creating space for unpopular answers?
- Are you capturing answers you may disagree with?
- Are you supporting answers you may feel are not possible?
- Are you finding ways for everyone in the room to participate, even those who are socially anxious, shy, or have varying learning and participation styles?
- Are you able and prepared to respond to difficult comments with respect and thoughtfulness?

Creating a strong introduction that is built on shared values can be important in any shared space. You can also use a talking piece that is passed around the room to give everyone a chance to speak, even if they choose to "pass" or not speak when they have the opportunity.



In order for women to engage with each other in this context, the set up of the room is important. If everyone is facing the same direction (i.e. the front of the room), we are not fostering interconnection or collaboration. Having everyone face each other allows women to see each other's faces, relate to each other and respond to each other.

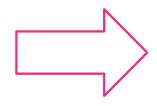
Ultimately, this process of engaging women in dialogue will identify ways to move forward and build a welcoming, community-oriented space.



**Note:** The use of a talking piece, often an item of significance to the group, allows for more balanced participation and facilitates a more democratic use of space.

### Moving from planning to change making

So you have created space for women to participate, listened to women's voices, and identified some next steps. Now what? A good way to keep women engaged in the process and foster ownership of the space is to re-engage them in the coordination and implementation of changes.<sup>34</sup> This may also help with some of the costs and logistics of the process. For example, was changing the paint colour in a room a recommendation? Provide some food and put out a call for help painting. Need art on the walls to make the space more inviting? Coordinate a call for art submissions from the community and have a committee select pieces. Women can also work together to create artwork that is meaningful to them. This process of engagement helps to build community, and creates a sense of ownership in the space.



"..to create a more positive and connected future for our communities, we must be willing to trade problems for possibilities"<sup>45</sup>





#### **CONNECT WITH COMMUNITY PARTNERS**

Throughout this process, you can reach out to and use other agencies in your community as resources. Identify other agencies that may have recently gone through renovations or policy updates. Consult with them about their process and models for change. Use and adapt some frameworks that you think align well with the changes you want to see at your organization. To find places to serve as good examples of welcoming spaces, go back to the women in your organization and ask them where they've felt safe and valued.

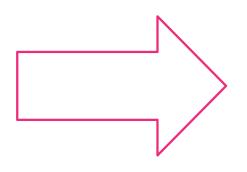
Additionally, it is a good idea to connect with your local HIV service organization. These organizations can provide your organization with safer sex and, sometimes, safer drug use supplies and provide tips on how to better incorporate HIV into your community organization. Your local WHAI Coordinator can work with you to draft and develop organizational strategies that will make your space more inclusive to women's HIV-related experiences, ensure your space is nonstigmatizing, and provide capacity building training to your staff.

Community partners make it so you don't have to embark on this process alone. Use your networks and share experiences and expertise with each other.



#### **BE INNOVATIVE**

Learning from community partners and established research is important because we can learn about successes and we can also learn about strategies that didn't work. But it's also important to try new creative ideas. We often use existing models and try to fit ourselves into frameworks that don't quite fit our needs. If your group comes up with something new and innovative, consider trying it. Engage the community in solving problems. Ask "how" instead of listing reasons why it is not possible. Creativity and innovation can foster important community changes. Remember that the women you are working with have a lot of expertise and if they are engaged in the community, they will also be invested in finding ways to create change.



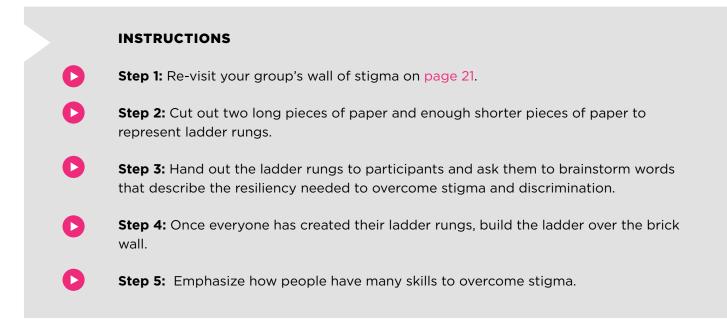






### Activity: Ladder of Resiliency

Building on the activity from page 21, "The Brick Wall of Stigma", use this activity to explore the many ways women overcome stigma and discrimination through resiliency and welcoming spaces. This activity will involve the creation of a ladder to demonstrate symbolic attributes that help communities "climb over" or overcome experiences of stigma.

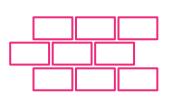


#### TAKE A MOMENT TO REFLECT

- Ask the group to discuss ways they can build these examples into their work to foster a welcoming space.
- Ask the group to identify activities they can commit to in their day to day work.



Here's how to make your own "Ladder of Resiliency."



**Step 1** Re-visit your wall of stigma.

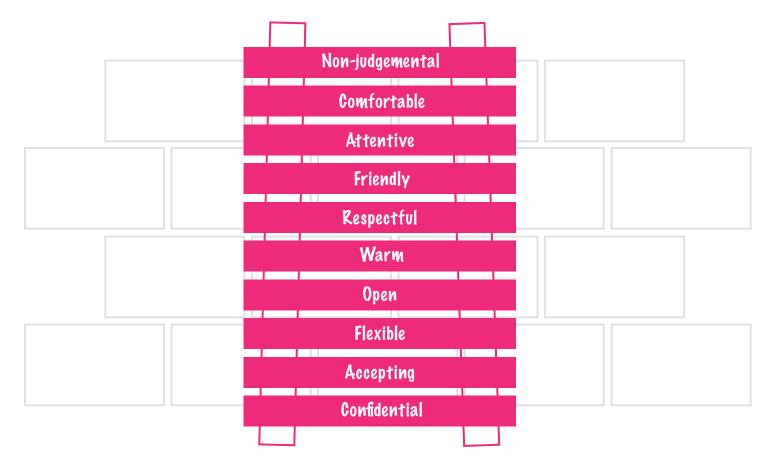


**Step 2** Cut out long and short pieces of paper to create a ladder.



#### Step 3

Brainstorm words that describe the resiliency needed to overcome stigma and discrimination. Common words that women have used to describe welcoming spaces are displayed on the ladder below.<sup>35,37,46</sup>



#### **Step 4** Assemble your "Ladder of Resiliency."



#### **MOVING FORWARD**

Women who use your organization are looking for care and assistance; many have had unsuccessful interactions in the past and have been traumatized as a result. Now that you have received training about stigma and discrimination you can facilitate changes in your organization to ensure that women who utilize your community organization feel welcome and can participate without judgment or discrimination.

This resource was created by the Women & HIV/AIDS Initiative of Ontario with input from many people. Thank you to everyone who took the time to share their insights, ideas and passion. Thank you especially to the women who's voices are used throughout this document. Your willingness to share your experiences is invaluable.

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