SECTION 1

An introduction to stigma

IN THIS SECTION

Stigma: an introduction

WELCOME

Our community organizations are an integral part of Ontario's response to HIV, particularly amongst **women** living with HIV or facing systemic risk related to HIV. By creating what we're calling "welcoming spaces," community organizations have the capacity to build strong, inclusive communities that fight stigma and discrimination. These spaces are meant to make **women** feel appreciated for their knowledge and skills without facing judgment. Here, they can actively shape and fulfill their own needs as individuals in WHAI's priority population. It's not just about doing what's right; it's part of our commitment to the Ontario Human Rights Code.[2]

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 culture and atmosphere. It also involves understanding the many ways **women** experience stigma and discrimination in our communities. Creating a welcoming space is an ongoing process that needs continuous attention, dedication, and thoughtfulness. It involves staying committed and being mindful of the evolving needs of the people and communities who contribute to shaping it.

Section 1: An introduction to stigma in this toolkit is designed to explore **women**'s experiences of stigma and discrimination in the following sections:

- **Stigma** see page 3
- **Types of stigma** see page 5

Section 2: Creating Welcoming Spaces provides tools to help dismantle stigma and create a welcoming space at your organization in the following sections:

- **Creating welcoming spaces** see page 2
- **Strategies to create welcoming spaces** see page 16

Note: The **social determinants of health** are the non-medical factors that influence health outcomes. These can be thought of as "structural factors" and include "all social and political mechanisms that create hierarchies of position and power that determine individuals' and communities' access to resources. In other words, social determinants of health are the conditions in which people are born, grow, work, live, and age. They capture the structural, political, and institutional forces that shape the conditions of daily life. **Examples of social determinants of health include:**[3]

- Income levels
- Housing
- Employment
- Food access
- Violence

Social determinants of health cause health disparities, and they are the reason why individuals and communities with more power and privilege tend to have better health outcomes than those who have been historical marginalized. Experiences of racism, colonization, and discrimination negatively affect individuals' and communities' conditions of daily life and their health, often spanning generations.[3]

FOR MORE INFORMATION

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

www.whai.ca/resources

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.[5,6,7]

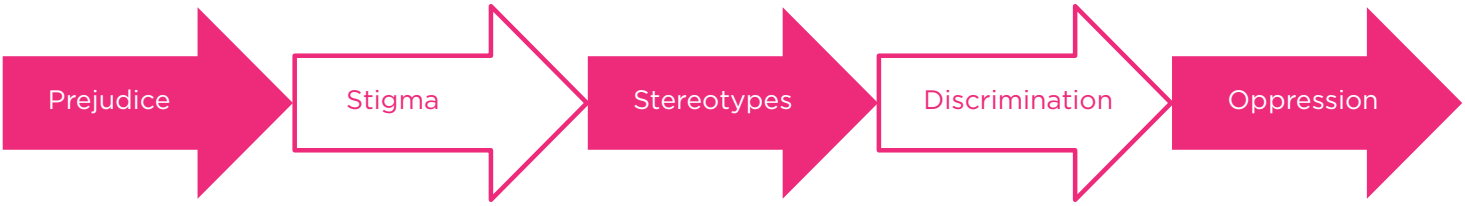
The process of stigma leading to discrimination and oppression is often sequential. For example, a belief (prejudice) about one person (stigma) is then applied to a group of people (a stereotype) and this impacts behaviours and actions towards those people (discrimination and oppression). In this way, discrimination and oppression are the enactment of stigma.[8] As such, stigma is an important area of work for community organizations in trying to address unequal treatment and oppression.[7]

DID YOU KNOW

Research has long shown that race and economic vulnerability drive higher incidence of HIV.

44%

of the **women** diagnosed with HIV for the first time in 2020 were African, Caribbean, or Black, despite the fact African, Caribbean, and Black communities make up 5.5% of Ontario's overall population.[4]



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.[8] 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.[9,10] 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".[11]

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.[8]

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.[7]

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.[11,12] Women are still dealing with judgement about how they contracted HIV and what it means to live with HIV.[8,9,13,14] This can often be a traumatizing experience for women. Not to mention, racial disparities inform both incidence of HIV and access to appropriate care, meaning that even with women, some face unique barriers that stem from the compounding impacts of gender and race. Research has confirmed that the higher rates of HIV among Black women are linked to sociodemographic and socioeconomic factors.[15] These factors are key drivers of HIV-related stigma today, contributing to increased risk for women to contract HIV and reduced health outcomes for women living with HIV.

THE IMPACT OF COVID-19 ON HIV-RELATED STIGMA

The global impact of the COVID-19 pandemic has been widespread, affecting people from all walks of life. However, it's important to acknowledge that the ongoing repercussions are particularly challenging for individuals with compromised immune systems, including those within the WHAI priority populations, as well as women living with HIV.

Despite high rates of the virus and risks posed to immunocompromised people[45], safety precautions such as masking and limits on gathering size are no longer mandatory. This demonstrates how policies often prioritize the privileged while the historical experiences of stigma determine who is left behind. To address this issue, this toolkit includes practical recommendations to make spaces more welcoming for those who are immunocompromised or disproportionately affected by the spread of viruses and illnesses. It also offers suggestions to facilitate activities in online settings.

STIGMA THROUGH A MEDIA LENS

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

Reflect on the following questions:

1. What are the dominant messages related to HIV embedded in media?
2. What faces are attached to HIV in the media?
3. 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."[16]

– A woman living with HIV

Types of stigma

"HIV stigma affects the quality of life, health opportunities received and sought, and psychological well-being of HIV positive **women.**"[12]

– A support worker

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 2SLGBTQ+ communities.

Institutional stigma

Internalized stigma

Social stigma

Stigma by association

Institutional stigma

The policies, protocols, and procedures embedded in our societal institutions such as governments, legal systems, schools, and community organizations can perpetuate stigma against certain populations. Institutional stigma operates at the systems level, involving policies that intentionally or unintentionally cause harm. Three examples of institutional stigma explored below are the health care system, the legal system, and the shelter system.

> "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."[16]
>
> - *A woman living with HIV*

THE HEALTH CARE SYSTEM

While many people have positive experiences accessing health care, research has also documented experiences of stigma and discrimination that people face in the healthcare system. This is especially true amongst WHAI's priority populations. In some cases, people report being treated in a stigmatizing way by healthcare professionals because of their HIV status, race, or gender.[18] Sometimes, this is rooted in a flawed fear of contracting HIV, and other times it is rooted in judgement about how a **woman** contracted HIV, or about they identities they present.

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.[43]

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

- Blamed people living with HIV for their status
- Refused care to people living with HIV
- Made fatalistic comments
- Mocked them
- Labelled people living with HIV
- Physically abused patients living with HIV[14]

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

It is important for community organizations to be thoughtful about **women**'s experiences in the healthcare system, support **women** accessing health care, and educate healthcare providers about HIV and the impact of stigma.

> "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*

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;[20,23] however, shelter policies can also contribute to institutional stigma. For example, **women** are sometimes asked to give their medications to staff for safe keeping and regular dispensing. For many **women** living with 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.[24] Gender segregation and transphobia create barriers for Trans people seeking shelter services who also report experiencing discrimination and feeling unsafe when accessing emergency housing supports. As workers in community organizations and shelters, it is important for us to understand these experiences, to support **women** who are accessing shelters,[25] and to engage people working at shelters to learn about institutional stigma and creating meaningful change.

"It is important for us to remember women who have been in prison. And who are currently in prison. They are part of our community too but there are so many barriers to ensuring they're included in our work to make communities inclusive. Even when women are first out of jail - they are at so much risk of being criminalized because of the lack of community inclusion."

- *A community worker*

"There is a lot of fear about HIV criminalization. There are a lot of confusing pieces about the law and how it might be used. And how it impacts rights. This is especially true for women in violent situations and also women who have children."

- *A community worker*

THE LEGAL SYSTEM

The legal system aims to enforce Canadian laws using principles of justice and equality. 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 for life. 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.[19] This is evident in statistics about who is charged. As of 2022, there have been at least 224 prosecutions for alleged HIV non-disclosure in Canada. Black people represent 22% of those criminally charged under this offence, despite only making up 3.5% of the Canadian population.[19]

Indigenous **women** are also targeted by HIV non-disclosure laws. Since 1989, race data was collected in 15 out of the 19 instances where **women** were charged. In these cases, 33% involve Indigenous **women** - who only make up 4% of the overall population of **women** in Canada.[20]

ANTI-BLACK & ANTI-INDIGENOUS RACISM IN THE LEGAL SYSTEM

The legal system has been historically enforced in ways that uphold systems of racism and settler colonialism. For instance, Black Canadian communities are overrepresented in the legal system. The Ontario Police Special Investigation Unit (SIU) found that while Black people only form 8.9% of Toronto's population, they make up 25.4% of SIU investigations; 28.8% of cases involving police use of force, 36% of police shootings, 61.5% of police use of force cases that resulted in civilian death, and 70% of police shootings that resulted in civilian death.[26]

Black people also make up 7.2% of people within federal prisons while comprising only 3.5% of the overall Canadian population aged 15 and older. Further, it was found that incarcerated Black men and **women** were significantly more likely to come from low-income and underserved communities, demonstrating the relationship between marginalization and overrepresentation in the criminal justice system.[27]

Indigenous communities in Canada are similarly targeted by the legal enforcement. Data indicates that numbers of incarcerated Indigenous people are rising, growing from 20% to 28% of the overall incarcerated population in 10 years, despite only representing 4.1% of the overall Canadian population. In the same period that this growth took place, the number of non-Indigenous male offenders decreased slightly. Meanwhile, Indigenous **women** are incarcerated at a rate 12.5 times higher than non-Indigenous **women**, demonstrating the intersecting effects of settler-colonialism and gender-based violence.[28]

In addition to Black and Indigenous communities, Trans communities (particularly, Trans **women**), sex workers, and people who have migrated are also disproportionately targeted and overrepresented within the legal system, particularly as these identities and experiences overlap and intersect with racialized identities. Not to mention, the effects of any interaction with the legal system[25] (federal or provincial incarceration or even just repeated interactions with the police) have significant effects on individuals' lives after the fact.[28]

Stigmatizing policies within institutions can have devastating consequences for individuals and communities. Criminal records result in excessive surveillance, and formerly incarcerated individuals are often required by law to disclose their record to employers, significantly affecting their ability to find meaningful employment and earn a living income. In some instances, criminal records can even be used to prevent an individual from living in particular neighborhoods and contribute to social stigma, internalized stigma, and an overall culture of heightened stigma. This stigma not only affects people who have experienced the legal system, but communities who are viewed as "disproportionately criminal", creating narratives of danger that obscure the racism, discrimination, and inequality embedded in our institutions. As such, this system not only takes advantage of existing forms of marginalization, but often worsens existing inequities in society.

> "Women have a lot of fear of the child welfare system, the legal system if HIV+ women have children, fear of the police, especially if leaving an abusive situation, fear of stigma in emergency care and more. This is especially true for Indigenous and Black women in our community."
>
> - *A community worker*

Social stigma

> "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."[29]
>
> - *A woman living with HIV*

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.

> "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."[29]
>
> - *A woman living with HIV*

SEXUALITY

Not all forms of sex are embraced by society. Some people may have one partner or many partners, and others may engage in a variety of sexual activities.

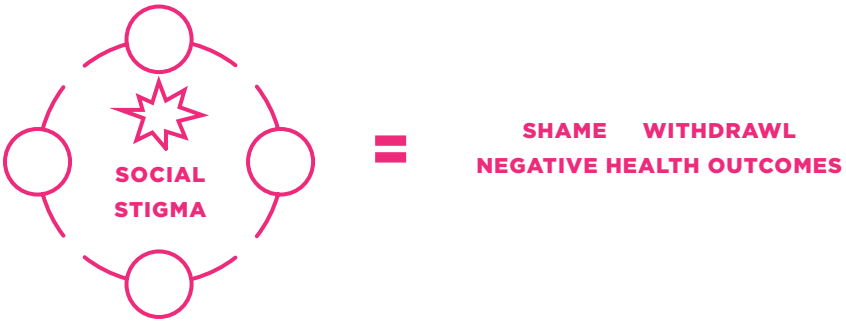
Communities within WHAI's priority populations are often stereotyped as hypersexual resulting in stigma, scrutiny, and blame for HIV. This is particularly pronounced for Black, Indigenous, and racialized **women**; **women** who use drugs; Trans **women**, 2-Spirit and Non-Binary people; and **women** who engage in sex work.

"Because it's sexually transmitted people look at it like you're dirty, you're not clean, bringing it on yourself."[29]

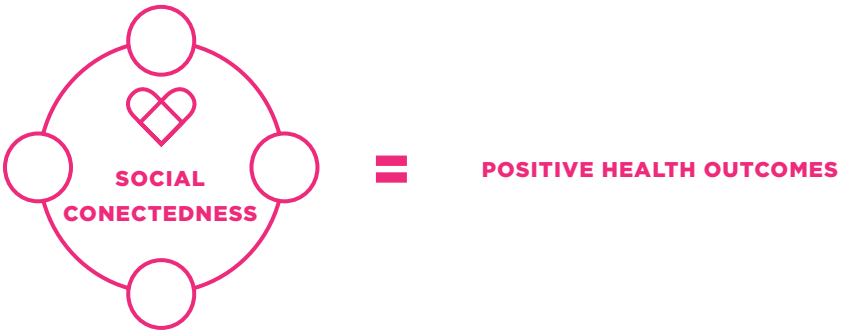
- A woman living with HIV

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."[31]

- A sex working woman living with HIV



Conversely, strong, supportive social connections are shown to positively impact **women**'s health.[40] It is important that our community organizations understand social stigma, and work to build inclusive, supportive spaces.



Stigma by association

Stigma by association, also called 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.[7,35] In this context, stigma by association is when people experience judgment because of their relationship with a group perceived to be carriers of HIV. Examples of this type of stigma would be the judgment an individual might face from others for having a relationship with someone who uses drugs, or the assumptions that are made about someone's HIV status based on their perceived racial identity or country of origin.

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.

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.

"I'm dying of sadness, having to hide this."[34]

- *An African Caribbean 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

STIGMA BY ASSOCIATION IN NUMBERS

In a Canadian longitudinal survey looking at attitudes and knowledge about HIV:[38]

18%

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

35%

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

54%

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

Internalized stigma

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."[34,40] 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.[33] 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.[39] 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.[32] 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."

5X

Rates of depression among HIV-positive **women** from African, Caribbean, and Black communities in Ontario are five times higher than Canadian statistics.[43]

"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."[29]

- 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."[29]

- A Caribbean 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?
5. How might internalized stigma impact a **woman**'s ability to ask questions about accessibility and have her needs accommodated?

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.[33]

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. TThis concept is referred to as intersectionality and was coined by the legal theorist Kim Crenshaw to describe the phenomenon of the interconnected experiences of racism and misogyny faced by Black women.[44] When people's lives are subject to several of these categorizations, multiple and overlapping oppressions create greater barriers to achieving positive health outcomes. 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.[43] 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 affect the delivery of important healthcare services, which in turn determines whose health is prioritized and who is served.

Cisnormativity means Trans women face barriers to accessing Trans-affirming HIV and sexual health resources.

Some of these barriers may include experiences of discrimination and stigma at sexual health clinics.

As a result, Trans women may have reduced access to preventative measures and resources to support their sexual health needs compared to cis people.

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