

# Training Peer Mentors: Facilitation Guide

## Module 12a: HIV-related Stigma

### What to Expect

Module 12a examines different kinds of stigma experienced by people living with HIV.

#### Presenting Opening Points: Understanding stigma

Whether it's internalized, a personal interaction, or at a policy/legal level, stigma is a reality. Even with modern medications, many people with HIV live long, productive and engaged healthy lives. Yet stigma never went away! It continues to act as a profound stressor negatively affecting care, treatment, and support.

HIV-related stigma has been defined in many ways, including prejudice, discounting, discrediting, and discriminating, directed at people who are perceived to have HIV<sup>1, 2, 3</sup>. It is intimately linked to human rights violations<sup>4</sup>. Stigma lives in the misconceptions about how HIV is transmitted and from judgmental attitudes towards social groups that are disproportionately affected by HIV; including men who have sex with men, people from endemic countries, ethnic minorities, Indigenous people, and people who use illicit drugs. According to the Global Network of People Living with HIV/AIDS, (PLHIV) the biggest challenge facing people living with HIV is stigma and discrimination.<sup>5</sup>

People living with HIV in Canada and the organizations that serve them report that HIV-related stigma is pervasive, complex, and related to other forms of discrimination and marginalization<sup>5, 6</sup>. For example, service providers report that immigrants from countries where HIV is endemic often fail to seek out care they need in Canada because of the stigma associated with HIV<sup>7</sup>. Issues of self-blame for seroconversion<sup>8</sup>, gender-based violence and financial dependence for women<sup>7</sup> have also been found to compound HIV-related stigma in many Canadian contexts. For Indigenous people living with HIV/AIDS (APHA), stigma is intimately connected to experiences of housing discrimination<sup>9</sup>, family disruption, cultural disconnection<sup>10</sup>, and poor treatment when seeking HIV testing and care. These range from discrimination, fear and avoidance, to outright hostility<sup>11,12</sup>. Stigma is an added layer which exacerbates the inequalities people already suffer.

PLHIV who do not have legal status in Canada often do not have access to health care, leading them to be tested for HIV at a later stage of the illness<sup>13</sup>. Further, research has found that people who use injection drugs often avoid using formal health and social services because they are unwelcome, fear the consequences, have been discharged from care, and/or the services are not designed to meet their needs<sup>14</sup>. These points highlight the importance understanding the intersecting forms of HIV-related stigma across different Canadian contexts, and also illustrates the diverse resilience factors (social and personal resources), so that participants (Peer Workers) can take action and improve the health outcomes of their communities and the peers they work with.

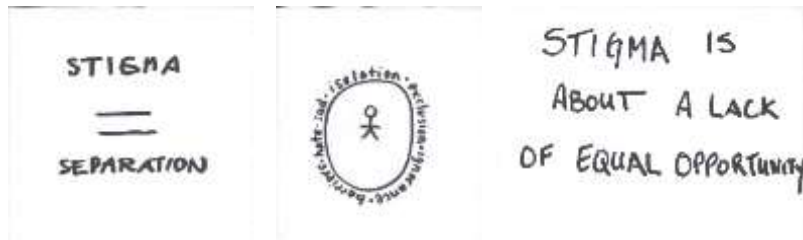
## Activity: What does Stigma mean to you?

### Purpose:

Section one starts with the participants' own experience of and feelings about being stigmatized and stigmatizing others. The aim is to get participants to connect to the issue on a personal-emotional level, rather than a theoretical level (through a definition) although that will also be covered. This will assist participants in the understanding that stigma is a profound leveler and thus we all have much in common despite our differences (Social, cultural, gender, sex, ethnicity etc.).

### Materials needed:

1. Black felt markers
2. White paper
3. Tape



### Process:

1. Get participants to reflect on what stigma means to them. It could be an image, a word or thought. It could even be a situation. Ask participants to not put their names on the paper or the names of anyone else, this includes Agencies, Doctors etc.
2. After about one min ask participants to draw an image, or right the word that best expresses what stigma means to them.
3. When participants are finished collect all the sheets of paper
4. Have one trainer/facilitator tape to a wall while the other starts to discuss the activity.
5. Once taped to the wall, ask participants to reflect pointing out any interesting clusters of images or words, also draw attention to any anomalies.
6. Have a discussion about this experience.

### Discussion Questions:

1. What was that like for you? Hard? Easy? Why?
2. What are some of the common features across of the works on the wall?
3. What does this show?
4. Who do you think is responsible for changing stigma? Just the people who stigmatize?
5. What part do you think you can play?
6. Do you ever stigmatize others? What about in the language you use?

## Summary Discussion Points: What does Stigma mean to you?

Stigma is not someone else's problem, it all of ours. There may be a feeling of 'us and them', but it's a social issue that matters to all Canadians. People who are stigmatized are marked out as being different and are blamed for that difference. It's hard to imagine but there are people living with HIV, who may or may not know it, but they stigmatize people living without the virus frequently.

We ALL stigmatize!

We stigmatize when:

- We say things like "*she/he/they was promiscuous*" and "*he/she/they deserves it*"; and
- We ask questions "*Where did you get HIV from*".
- We isolate PLHIV as well as other groups by excluded them from decision-making.

We are all part of the problem even if at first we don't recognize it. This is not just within the HIV community, but in society in general. Stigma hurts us all not just the people living with HIV. As peer workers once we understand what stigma is about and how it manifests in different contexts, we then will be better able to support the peers we working with, and take appropriate action.

**Note:** Participants may want to problem solve; this is not the time for that. Setting participants expectations early will set the tone of the discussion, hopefully away from problem solving. It's also important to recognize that for some participants this discussion could be emotionally triggering.

## Discussion: What is the meaning of Stigma?

**Purpose:** Participants will be able to define the meaning of stigma and recognize the three different kinds.

**Process:** Trainer/facilitator leads group discussion starting with definition and moving in to the three forms of stigma.

### Etymology of stigma

Stigma (n.)

1590s (earlier *stigma*, c. 1400), "mark made on skin by burning with a hot iron," from Latin *stigma* (plural *stigmata*), from Greek *stigma* (genitive *stigmatos*) "mark of a pointed instrument, puncture, tattoo-mark, brand," from root of *stizein* "to mark, tattoo," from PIE root *\*steig-* "to stick; pointed" (see *stick* (v.)).

Figurative meaning "a mark of disgrace" in English is from 1610s. *Stigmas* "marks resembling the wounds on the body of Christ, appearing supernaturally on the bodies of the devout" is from 1630s; earlier *stigmat* (late 14c.), from Latin *stigmata*.<sup>1</sup>

Stigma is a spoilt identity. To stigmatize is to label someone, to see them as inferior because of an attribute they have, like HIV.

For those living with HIV, the knowledge that their HIV status is a socially devalued aspect of the self may be experienced through three mechanisms: *enacted stigma*, *anticipated stigma*, and *internalized stigma*.

- *Enacted stigma* refers to the extent to which people with HIV have actually experienced prejudice and discrimination from others.
- *Anticipated stigma* represents expectations that they will experience prejudice and discrimination in the future.
- *Internalized stigma* refers to the endorsement of the negative beliefs and feelings associated with HIV about themselves.

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<sup>1</sup> <https://www.etymonline.com/word/stigma>

## Presenting: What is the meaning of Stigma?

**Purpose:** To open participants up to the concept that stigma comes in different forms, has wide ranging effects and comes from different places

### Process:

1. Create handout or power point called “Three forms of Stigma” ahead (from previous page)
2. Review handout/powerpoint “Three forms of Stigma”
  - **Enacted stigma:** refers to the extent to which people with HIV have actually experienced prejudice and discrimination from others  
**Example:**
  - **Internalized stigma and Identity:** Internalized stigma refers to the endorsement of the negative beliefs and feelings associated with HIV about themselves.  
**Example:**
  - **Anticipated stigma:** represents expectations that they will experience prejudice and discrimination in the future.  
**Example:**
3. Lead the participant group through a group discussion.

### Discussion Questions:

1. Why as peer workers do you feel it’s important to understand the three forms of stigma?
2. Can you give me an example of \_\_\_\_?
3. Do these make sense with what have experienced?
4. How do you think Enacted stigma is different than anticipated?

**Note:** you can also have participants read the quote from the handout to make each point real, and then talk about what they have just read on the Handout or PowerPoint. Scan the room and adjust discussion and questions based on the group’s responses.

## Activity: Stigma in different contexts

**Purpose:** Allows participants to understand that stigma may look different when presented in different contexts. Participants will be able to identify the effects of stigma on different players and institutions.

### Process:

1. Break participants in to groups of two
2. Pass around sheets of paper with the titles
  - **Health/disease status and self-perception:**  
This will consider how people see themselves as healthy and/or sick and how that can affect their wellbeing. E.g.: serosorting; achieving undetectable (HIV), achieving/maintaining the “cure” status for HCV. Self-blame for “bringing this on myself”
  - **Ethnic, cultural and sexual identity:**  
One’s formative culture can have a deep impact on identity and stigma. A homophobic family and social culture can be extremely stigmatizing to a young queer person; add HIV and/or drug use and it’s even more complex.
  - **Secrecy and disclosure**  
Where is it safe to speak? Keeping one’s health/disease status a secret is an emotional stress, yet there may be no safe place to disclose
  - **Social groups and societal stigma:**  
Within one’s chosen social circles, layers of stigma may be present. People can experience stigma as a result of disease status; inclusion and exclusion in groups based on health status (treatment uptake status); drug use status; treatment “success” status
  - **Society at large:**  
The circles in which people move that are beyond their control can exert stigma in many ways: workplaces; obligatory social events; families; community events.
3. Ask participants to brainstorm and write down what might stigma look like in each of these contexts?
4. Ask participants to think of who is impacted by stigma in these contexts. Is it just the person living with HIV?
5. Have the two person group to report back to the rest of the group
6. Once all groups have reported back, discuss

### Discussion questions:

1. TBA (Trainer/facilitator discretion)

## **Presenting: How are the basic rights of PLHIV denied?**

**Purpose:** Participants will be able to recognize that PLHIV have rights and responsibilities just like other people and recognize that PLHIV rights are often denied.

People living with HIV have the same basic rights and responsibilities as all other citizens of the country. Human rights violations in the context of HIV can take many forms.

Human rights violations in the context of HIV include; the criminalization and the enactment of punitive laws which target key populations and people living with HIV, as well as stigma and discrimination in the workplace and in healthcare services, gender inequality, and the denial of access to HIV services. These can worsen the impact of HIV, increase vulnerability to HIV and more broadly, undermine responses to the epidemic.

### **HIV criminalization**

HIV criminalization refers to laws that criminalize people living with HIV based on their HIV status. This can be via HIV-specific laws or general criminal laws that prosecute:

- unintentional HIV transmission
- potential or perceived exposure to HIV where HIV was not transmitted
- non - disclosure of known HIV-positive status

The rationale behind these laws is to deter perceived “morally unacceptable behavior” through fear of punishment. However, a wealth of evidence shows how HIV criminalization is a poor public health strategy and actually undermines the response to HIV.

**Example:** HIV criminalization has been shown to deter people from testing for HIV and as a result, limit access to treatment and care.

### **Criminalization of people who inject drugs**

The criminalization of drugs and the people who use them increases the risk of HIV and other health problems. Fear of arrest or police abuse drives people who inject drugs away from vital HIV and health services, while increasing unsafe practices

Even at government sanctioned harm reduction programs, the presence of police drives people away from these services out of fear of arrest or other punishment.

### **Criminalization of sex workers**

Criminal laws specific to sex work are used to criminalize sex workers clients as well as families, partners and friends of sex workers. As well as sex work specific laws, there are a number of other laws that create the conditions for criminalization.

These laws and laws and practices fuel stigma, discrimination and violence towards people in sex work. Anti-prostitution laws and policies that criminalize or legally oppress sex workers allow widespread human rights abuses by state authorities.

This includes verbal, physical and sexual abuse; mandatory HIV testing; the public 'naming and shaming' of sex workers in the media; forced evictions; and extortion. The risk of violence is heightened for sex workers living with HIV who are also subject to HIV laws around non-disclosure, exposure, and transmission law.

### **Discrimination by healthcare workers**

In many parts of the world, even in Canada, healthcare sometimes is not confidential and health care systems and people working in them can be rife with judgements about a person's HIV status. These views are fueled by a variety of factors, including ignorance about HIV transmission routes.

This prevents many people from being honest to healthcare workers when they seek medical help and deters others from seeking, using and adhering to HIV prevention and treatment services.

### **Discrimination in the workplace**

In some places, people living with HIV can be refused the right to work, while in the workplace, they can suffer from discriminatory practices such as termination or refusal of employment because of their HIV status.

This prevents people living with HIV from earning a living and as a result they may be unable to afford to pay for antiretroviral drugs (excludes BC) and other HIV services, or more generally, suffer from financial instability.



## Presenting: GIPA/MIPA

**Purpose:** Introduce the concept of GIPA/MIPA, have a conversation about why rights are important by giving an over view of the historical fight for quality within the HIV movement.

### Resources:

### Process:

1. Create a GIPA PowerPoint based on the sample GIPMIPA PowerPoint.
2. Ask participants if they know what GIPA means or if they have heard it?
3. Debrief briefly.
4. Move through the GIPA PowerPoint while putting emphasize on the history behind GIPA, and why there was a need.
5. Explain the history of GIPA.
6. Review the different models of involvement and remember to stress that it is up to the individual how much or how little they would like to participate. It is about choice and agency, and it is important to recognize that there are different levels.
7. Define and review the other principles: MIPA, MEPA, MIWA – found in the PowerPoint.
8. Make connection that people living with HIV are enacting GIPA in many ways; for example Peer work.
9. Refer to the handouts (attached at the end of this module) and provide a copy for participants to review:
  - a. Copy of PowerPoint with space for notes
  - b. From Principle to Practice: Greater Involvement of People Living with or Affected by HIV/AIDS (GIPA)
  - c. History and Foundation of GIPA – Greater Involvement of People with HIV/AIDS
  - d. Pyramid-circle of GIPA Involvement
10. Videos from the 30/30 campaign to show a history of HIV told by and for those who were there.<sup>2</sup>

### Speaker's Notes: (Adapt as needed)

*“GIPA is not a project or programme GIPA or the Greater Involvement of People Living with HIV is critical to halting and reversing the epidemic; in many countries reversing the epidemic is also critical to reducing poverty. It is a principle that aims to realize the rights and responsibilities of people living with HIV, including their right to self-determination and participation in decision-making processes that affect their lives. In these efforts, GIPA also aims to enhance the quality and effectiveness of the AIDS response<sup>15</sup>*

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<sup>2</sup> <http://3030.aidsvancouver.org/>

We can learn a lot from understanding where we've come from. The History of the HIV movement has catalyzed networks of Positive folks who wanted change. They built new communities, saved old ones, they have become activists, enlisted the help of academics, all to fight for better treatment in all facets of society. Our community connections and history provide pathways to fighting stigma of all kinds. Many of these important social and political developments were made possible by the work of the numerous people living with HIV. Folks, like you, who created movements, policy change, organizations, communities, which have all emerged in response to the HIV epidemic<sup>16</sup>

### **It all began with the Denver Principles**

“The idea that personal experiences should shape the AIDS response was first voiced by people living with HIV in Denver in 1985.”<sup>17</sup>

There is no better way to cite the history of the PWA self-empowerment movement than to quote the principles articulated in Denver in 1983. They are as relevant and powerful today as they were then. Refer to the picture of the founders and read:



**“We condemn attempts to label us as "victims," a term which implies defeat, and we are only occasionally "patients," a term which implies passivity, helplessness, and dependence upon the care of others. We are "People with AIDS."”**

### **Paris UN AIDS Summit**

“The GIPA Principle was formalized at the 1994 Paris AIDS Summit when 42 countries agreed to “support a greater involvement of people living with HIV at all...levels...and to...stimulate the creation of supportive political, legal and social environments”.

18 In 2001, 189 United Nations member countries endorsed the GIPA Principle as part of the Declaration of Commitment on HIV/AIDS. The 2006 Political Declaration on HIV/AIDS unanimously adopted by 192 Member States at the 2006 High Level Meeting on AIDS also advocated the greater involvement of people living with HIV.”<sup>19</sup>

## Discussion: The HIV community can reaffirm these rights

**Purpose:** Gets participants thinking about the tools they can use to effect change.

### Discussion Questions

1. Have you heard of the Declaration of Commitment on HIV, which protects the rights of people living with HIV?
2. If yes, have you ever read or discussed the content of this Declaration?
  - a. **Give Handout:** Declaration of Commitment on HIV/AIDS
3. Have you heard of the Canadian Charter of Rights and freedoms which protect(s) the rights of people living with HIV in this country?
  - a. **Give Handout:** Canadian Charter of Rights and Freedoms.
4. What groups or organizations can you turn to for help?
5. What about research?
6. Things You Can Do Yourself as Individuals?
7. Things You Can Do to Involve Others?
8. Things to Get the Community talking about and Acting against Stigma?

**Note:** Trainer/facilitator to have current and updated hand out so that participants have tangible takeaways. Have current examples of people fighting stigma or challenging policy

## Activity Flip Chart: Looking for Solutions in Different Contexts

**Purpose:** and participants will be able to develop a strategy for changing attitudes and behavior in a specific context. Agree on how they themselves and the HIV community can reaffirm those rights by introducing new tools.

### Process:

1. Ask the group: *What specific actions can you, as a peer mentor, implement that to help address these key factors relating to stigma?*
2. Flip chart participant's responses
3. When finished look for clusters of responses
4. Question: Do you think that you should respond the same way in each situation? Would you respond to stigma from health care providers the same way as a building manager?
5. Review hand out of: *Systems thinking*; taking action in different situations requires "systems thinking" there's no one size fits all solution

## Activity Review and Summarize

**Purpose:** Trainer/facilitator wraps-up at the end of the module - it is a quick review, to remind participants what it was that they learned.

**Process:**

1. Review the key points of the material
2. Over view of conclusions from the module
3. Review the key tools outlining the rights or PLHIV
4. Describing when and where participants can use this new information.
5. Review resources
6. Any questions?

## Activity Closing: What would a world without stigma look like?

**Purpose:** to get participants into a positive mind set for the trip home

**Process:**

1. Show Stigma Index Videos: “What would a world without stigma look like?”<sup>3</sup>
2. Ask participants to reflect on the first activity “What does stigma look like?”
3. Remind that now they have all the tools to readdress discriminations because of HIV stigma
4. Recognize that when participants get home they may be processing a lot of information, and their own feelings around stigma might come up. This is okay.
5. Get participants to write one positive thing they will do for self-care in their journals
6. Pass out info sheet on resources they may benefit from when at home

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<sup>3</sup> <https://vimeo.com/panbc>

## Resource Handouts/PDFs/PowerPoints

1. [Systems Thinking – Stigma](#)
2. [Presenting GIPAMIPA – Sample PowerPoint](#)
3. [Declaration of Commitment on HIV](#)
4. [GIPA – Best Practice Document](#)
5. [History and Foundation of GIPA](#)
6. [Pyramid - Circle of GIPA Involvement](#)
7. [Stigma Participant Resource List](#)

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## References/Resources

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- <sup>2</sup> Goffman E. *Stigma: Notes on the Management of Spoiled Identity*. Englewood Cliffs, N.J.: Prentice-Hall, Inc.; 1963.
- <sup>3</sup> Link BG, Phelan JC. Conceptualizing stigma. *Annual Review of Sociology*. 2001;27:363-85.
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- <sup>5</sup> Collins E, Cain R, Bereket T, Chen YY, Cleverly S, George C, et al. *Living & Serving II: 10 Years Later - The Involvement of People Living with HIV/AIDS in the Community AIDS Movement in Ontario*. Toronto: The Ontario HIV Treatment Network, 2007.
- <sup>6</sup> Travers R, Wilson M, Guta A, Bereket T, Flicker S, Rourke SB, et al. *The Involvement of People Living with HIV/AIDS in Community Based Research: Reflections from Ontario's HIV/AIDS Sector*. under review.
- <sup>7</sup> Tharao E, Massaquoi N, Teclom S. *Silent Voices of the HIV/AIDS Epidemic: African and Caribbean Women in Toronto 2002-2004*. Toronto: Women's Health in Women's Hands Community Health Centre; 2006.
- <sup>8</sup> Pawluch D, Cain R, Gillett J, Guenter D, Travers R. *Navigating HIV: A Study of Life with HIV*. Hamilton: HIV/AIDS Social Research Group, McMaster University, 2004.
- <sup>9</sup> Greene S. *Positive Spaces, Healthy Places – a prospective cohort study of 605 people living with HIV from across Ontario*. 16th Annual Canadian Conference on HIV/AIDS Research; Toronto 2007.
- <sup>10</sup> Jackson R, Prentice T, Cain R, Mill J, Barlow K, Collins E. *HIV and Depression: the Experience of Canadian Aboriginal People Living with HIV*. Ontario HIV Treatment Network; Toronto 2006.
- <sup>11</sup> Worthington C, Jackson J, Mill J, Prentice T, Archibald C, Wong T, et al. "A Little too Cold:" Aboriginal Youth speak about the Experience of HIV Testing. Canadian Association for HIV Research Conference; Quebec City, QC2006.
- <sup>12</sup> Archibald C, Prentice T, Jackson R, Worthington C, Wong T, Sommerfeldt S, et al. *HIV Testing and Access to Care: The Experience of Canadian Aboriginal Youth*. AIDS 2006 - XVI International AIDS Conference: Abstract no TUPE02372006.
- <sup>13</sup> Magalhaes L, Carrasco C, Gastaldo D. *Undocumented Migrants in Canada: A Scope Literature Review on Health, Access to Services, and Working Conditions*. *Journal of Immigrant and Minority Health*. 2010; 12: 132–151.
- <sup>14</sup> Strike CJ, O'Grady C, Myers T, et al. e. *Pushing the boundaries of outreach work: the case of needle exchange outreach programs in Canada*. *Social Science & Medicine*. 2004;59(1):209-19.
- <sup>15</sup> *The Greater Involvement of People Living with HIV (GIPA): UNAIDS Policy Brief (2007)* Author: UNAIDS, Accessed Online. Oct. 10, 2017 <[http://data.unaids.org/pub/briefingnote/2007/jc1299\\_policy\\_brief\\_gipa.pdf](http://data.unaids.org/pub/briefingnote/2007/jc1299_policy_brief_gipa.pdf)>.
- <sup>16</sup> *Ibid.*,
- <sup>17</sup> *Ibid.*,
- <sup>18</sup> *Statement from the advisory committee of the People with AIDS, Denver Principles 1984*. Accessed Online Oct 17, 2017. <<http://www.actupny.org/documents/Denver.html>>
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