

# HIV Stigma in African, Caribbean and Black Communities

## PURPOSE

People from African, Caribbean and Black (ACB) communities face multiple forms of stigma and discrimination. **HIV-related stigma** is just one of these. The purpose of this fact sheet is to raise awareness among health and social service professionals about the experience and impact of HIV-related stigma on ACB communities.

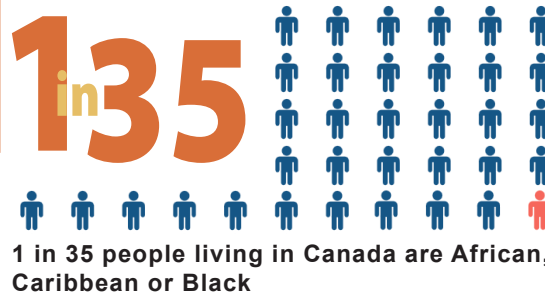
## STIGMA is a FEELING

Stigma is associated with attributes and behaviours which are seen by many people to go against norms or accepted ways of behaving in society. When a person has a quality that others see as different or bad, he/she is judged and experiences stigma.

HIV-related stigma refers to the negative beliefs, feelings and attitudes towards people living with or affected by HIV.

## HIV-related stigma stems from:

- Association with socially undesirable behaviours, such as sex outside of marriage, multiple sex partners, injection drug use, gay sex.
- A belief that acquiring HIV is the person's own fault.
- People living with HIV sometimes being members of other marginalized groups (e.g. African, Caribbean and Black people, men who have sex with men or MSM, Aboriginal people, people who inject drugs)
- Fear of HIV and its transmission.
- Ignorance about how HIV is transmitted.
- Fear of a disease that has no cure and its association with death.
- Homophobia.



In Canada, a disproportionate number of people living with HIV are from ACB communities. The estimated new infection rate among people from African, Caribbean and Black communities is about 9 times higher than among other Canadians.

## Why is there so much HIV-related stigma with African, Caribbean and Black communities?

Religious beliefs and norms, homophobia or the denial of homosexuality within communities, and silence about health and sexuality present major challenges to addressing HIV within ACB communities. Gossip and fear within communities lead to isolation of people living with HIV and discourages many from seeking testing, treatment or support services. The racialization of HIV as a Black or African disease by mainstream cultural media and institutions has a detrimental impact on access to HIV knowledge, health and support services.

## MULTI-FACETED STIGMAS

ACB people face intersecting and overlapping forms of stigma, discrimination and oppression.

Besides HIV-related stigma, people within ACB communities may also experience racism, sexism, homophobia, heterosexism, biphobia and transphobia.

The impact of HIV-related stigma is especially heavy on gay men, trans people, women, and individuals with low socio-economic status.

# EXAMPLES OF MULTI-FACETED EXPERIENCES OF STIGMA

**EXAMPLE:** “Many people living with HIV are choosing to become parents. Historically, Black women in Canada (and other women of colour) have been advised to have abortions. There is lots of stigma against PHAs who choose to conceive.”<sup>1</sup>

**EXAMPLE:** “ACB community members self-isolate, because of immigration concerns and stigma around HIV. They don’t want to come into the agency to talk to the ‘AIDS woman’ because AIDS Service Organizations are seen as gay organizations. And they don’t want anyone knowing that they have any kind of illness.”<sup>1</sup>

## EFFECTS of Stigma

- It labels and stereotypes people
- It devalues and dehumanizes people
- It leads people to blame those who are stigmatized
- It leads people who are stigmatized to feel ashamed (i.e., internalized stigma)
- It leads to the perception that stigmatized people are different and not as worthy as others
- It is associated with increased depression<sup>2</sup>
- It leads to DISCRIMINATION

## HIV-related stigma is a Vicious Circle

Stigma is an obstacle to HIV prevention, testing and treatment. People avoid testing because they fear a positive result and the stigma associated with it. For people living with HIV, fear of disclosure means that the virus remains invisible, which can lead to feelings of loneliness and despair. As a result, people may be reluctant to access health and social services. The continued stress and isolation caused by stigma can worsen the health of people living with HIV.

“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.”

~ Chantal (woman from Rwanda)

**FACT:** HIV-related stigma is the single greatest obstacle to HIV prevention and testing<sup>3</sup>

**FACT:** Approximately 26% (or 16,900) of people living with HIV in Canada are not aware of their status<sup>4</sup>

**FACT:** 38% of people believe that HIV-related stigma makes people unwilling to get tested for HIV<sup>5</sup>

1. EAST Research Team (2008). *The East African Health Study in Toronto (EAST): Results from a Survey of HIV and Health-Related Behaviour, Beliefs, Attitudes, and Knowledge*.
2. Logie C, James L, Tharao W, Loutfy M (2013). *Associations Between HIV-Related Stigma, Racial Discrimination, Gender Discrimination, and Depression Among HIV-Positive African, Caribbean, and Black Women in Ontario, Canada*. *AIDS Patient Care and STDs*, 27(2).
3. UNAIDS, *HIV-Related Stigma, Discrimination and Human Rights Violations: Case studies of successful programmes*, 2005.
4. Public Health Agency of Canada. (2014). *HIV/AIDS Epi Update - Chapter 1: National HIV Prevalence and Incidence Estimates for 2011*.
5. The CIHR Social Research Centre in HIV Prevention (2012). *HIV and AIDS in Canada: A National Survey*.
6. PHAC 2012 HIV/AIDS Attitudinal Tracking Survey.
7. Duke A & Women’s Health in Women’s Hands (2008). *The Woman I Have Become* (documentary film).

# What does HIV-related stigma FEEL LIKE?<sup>9</sup>

“My husband was ill... My mother asked me if I could just go for a test to find out. I did not take that very well. I actually became very angry with her. Because I said to myself, how can my own mother suspect that I could be HIV-positive?”

~ Lisungu (woman from Zimbabwe living with HIV)

“As an HIV/AIDS worker, or talking about it as a personal passion – people assume that I am HIV-positive. There is difficulty in getting people mobilized because of the stigma to even talk about it.”

~ Service provider

“When they told me, I went home and cried my eyes out for the whole night. He also tested positive. But up to this day he still tells people that he doesn’t have it.”

~ Rhonda (woman from Grenada living with HIV)

“I’m alive. But I don’t think I’m living in every sense of the word. Because I’ve locked myself away from society.”

~ Undisclosed person from the Caribbean 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.”

~ Undisclosed person from Caribbean living with HIV

## Findings from a 2011 national attitudinal survey on HIV and AIDS<sup>10</sup> (n=2,139) found that:

Despite the fact that **91%** of Canadians strongly agree that people living with HIV should have the same rights as they themselves do, including the same right to employment, health care and housing, **35%** of Canadians report at least some discomfort with their children attending a school with a child who is HIV-positive, and **54%** report that they would be at least somewhat uncomfortable with a close friend or family member dating a person living with HIV.

## Findings from a 2013 study<sup>11</sup> (n=173) on stigma and depression among ACB women living with HIV found that:

HIV-related stigma, racism and sexism all contributed to depression, highlighting the importance of looking at multiple forms of stigma and discrimination from an intersectional approach. However HIV-related stigma was most strongly related to depression, showing the need to address the ways that HIV-related stigma continues to impact mental health among ACB women.

## Findings from a 2004-2006 survey<sup>12</sup> of East Africans (n=456) living in the Greater Toronto Area on to HIV-related attitudes found that:

**55%** reported they would not eat in a restaurant where the cook was HIV positive. **33%** would want it to be kept a secret if a family member was HIV positive. **23%** would not want their child in a classroom with an HIV-positive child.

8. Duke A & Women’s Health in Women’s Hands (2008). *The Woman I Have Become* (documentary film).

9. Anonymous Service Provider (2013). Survey responses in research for Ontario HIV/AIDS Strategy for African, Caribbean and Black Communities 2013-2018.

10. The CIHR Social Research Centre in HIV Prevention (2012). *HIV and AIDS in Canada: A National Survey*.

11. Logie C, James L, Tharao W, Loutfy M (2013). Associations Between HIV-Related Stigma, Racial Discrimination, Gender Discrimination, and Depression Among HIV-Positive African, Caribbean, and Black Women in Ontario, Canada. *AIDS Patient Care and STDs*, 27(2).

12. EAST Research Team (2008). *The East African Health Study in Toronto (EAST): Results from a Survey of HIV and Health-Related Behaviour, Beliefs, Attitudes, and Knowledge*.

# The Role of HEALTH and SOCIAL SERVICE PROFESSIONALS

HIV-related stigma is a major public health issue. Indiscretions, lack of confidentiality and judgmental treatment from health care workers are **ESPECIALLY DAMAGING** and are a huge deterrent to testing and disclosure.

"The doctor called my house and asked me if I could come in. So when I went in, the doctor called my name and as I was walking to her office, she told me that I was HIV-positive. She didn't even wait until I was inside the room. At that moment, I just felt like: 'What is this? What is happening to me?'"

~ Paulina (African woman living with HIV)<sup>13</sup>

## ASK YOURSELF:

- How am I and/or my organization being inclusive and exclusive?
- Are we making specific efforts to enhance accessibility for those most at risk or hard to reach?
- How do I express and use my power and privilege?
- What assumptions and prejudgments am I making about my client or patient?
- Am I really committed to equity and social justice? If so, what more can I do to work towards it?

Health promotion practice emphasizes social justice and equity to ensure all people have an equal opportunity to experience good health through fair and just access to resources for health.

## CALL TO ACTION: What You Can Do to Fight Stigma and Build Empowerment

### As an Organization

- Identify and reduce barriers to services.
- Find, develop and make available high-quality, responsive and appropriate resources, regardless of their social position and conditions.<sup>14</sup>
- Target organizational investments and interventions towards the most disadvantaged communities and populations.<sup>2</sup>
- Support peer initiatives to reduce isolation, give voice to marginalized and at-risk individuals, and build knowledge and skills in the community.

### As an Individual Service Provider

- Identify and reduce barriers to services (especially when it is your own attitude).
- Recognize that ordinary people do the best they can to keep themselves healthy.
- Back up and support individual decisions, get consent and respect their autonomy and confidentiality.
- Build knowledge and skills in the community, client by client (or patient by patient).
- Generally be a positive, non-judgmental and helpful presence.

13. Duke A & Women's Health in Women's Hands (2008). *The Woman I Have Become* (documentary film).

14. HIV Edmonton (2015). *Ethical Care Workshop Materials*.

15. Anonymous Service Provider (2013). *Consultation survey response for Ontario HIV/AIDS Strategy for African, Caribbean and Black Communities 2013-2018*

"We should be having sex-positive conversations about sexuality and self-care, and all the other ways of taking care of ourselves as healthy sexual beings. We need to stop reinforcing fear and shame about Black bodies and sex."<sup>15</sup>

This fact sheet was developed by:



The Canadian HIV/AIDS Black, African and Caribbean Network (CHABAC) is a national network of organizations, individuals and other stakeholders who are dedicated to responding to issues related to HIV and AIDS in Canada's African, Caribbean and Black communities.