



## How African and Caribbean People in Toronto Experience and Respond to HIV Stigma, Denial, Fear, and Discrimination

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*African and Caribbean people are overrepresented among HIV infections in Canada. However, stigma related to HIV hampers HIV prevention efforts among African and Caribbean communities. In 2004, researchers from the African and Caribbean Council on HIV/AIDS in Ontario (ACCHO), the University of Toronto, and other institutions initiated a study to understand how African and Caribbean communities in Toronto experience and respond to HIV-related stigma, denial, fear, and discrimination. The study focused on three African and three Caribbean communities in Toronto.<sup>2</sup> It was based on interviews and focus group discussions with African and Caribbean women and men who were HIV-positive, HIV-negative, and those who did not know their status. This fact sheet<sup>3</sup> summarizes the study's key findings and participants' recommendations to address stigma. The italicized quotes throughout the text are excerpts from interviews and focus groups.*

### Out of sight, out of mind: HIV/AIDS in Toronto vs. 'back home'

*"...when you come here [to Canada] from an African country, you assume because they don't talk too much about it, there is no AIDS [in Canada]."*

HIV is not widely acknowledged as a local issue among African and Caribbean communities in Toronto. Very few people know someone who has been affected by HIV and only a small percentage of HIV-positive people publicly disclose their status. This has led to a false perception that HIV does not exist in these communities, especially when compared to the story of HIV in their countries of origin. There is also a common notion that an HIV diagnosis unavoidably leads to early death.

### Stereotyping who gets HIV

Experiences of stigma and discrimination related to HIV are very real in these communities. This refers to prejudiced, unjust, and unfair treatment directed at African and Caribbean communities in general, as well as at individuals and subsets of people within the communities who are perceived to be HIV-positive.

### ***"You're from Africa, you might have HIV": How race plays out***

In Toronto, many African and Caribbean people are subjected to stigma and discrimination that paints HIV as a 'black/African disease'. This plays out in various settings and relationships, including encounters with health care professionals and community-based health organizations. Consequently, African and Caribbean people have become more reluctant to seek HIV-related services and have responded by increasingly rejecting and mistrusting the health-care and social systems that, instead of supporting them, often discriminate against them.

### ***"If people were doing what they were supposed to do, they wouldn't get HIV."***

Stigmatizing attitudes toward HIV-positive people exist within African and Caribbean communities based on a range of inter-related assumptions about who gets HIV and why. In African and Caribbean communities in Toronto, people who are infected with HIV, or thought to be infected, are assumed to:

- Be homosexual (if the person is a man);

- Be sexually promiscuous (especially women);
- Have violated their cultural and/or religious moral code (for example, through sex outside marriage or sex with people of different cultural/religious backgrounds).

People identified as HIV positive are often marked as immoral and a shame to their family and community. Gossip, verbal harassment, ridicule, and ostracism are frequent community responses to people who are, or are assumed to be, infected with HIV.

Among African and Caribbean communities, homosexuality is generally stigmatized as unhealthy, immoral, or contrary to the perceived traditional cultural norms and values. The assumption that HIV/AIDS is a 'gay disease' or that gay men are to blame for HIV/AIDS compounds the stigma and negative attitude towards gay men in these communities, and may even hinder HIV prevention. As one man put it, *"Being homosexual, you're the bottom of the barrel. You add AIDS onto that, you're underneath the damn barrel...and then you're just totally shunned."*

### **Keeping quiet: Denial and the power of fear**

*"...sex is not something to be discussed openly, so it's difficult to have people discuss HIV."*

*"The way we are raised is to keep secret[s]...you're not supposed to talk to your community about your sickness."*

In general, African and Caribbean people are disinclined to discuss matters of health and sexuality amongst themselves. This facilitates denial of anything outside of what many interpret as traditional norms and creates a barrier to discussing and acknowledging HIV/AIDS.

***"HIV/AIDS is so controllable. And yet, because there's this huge silence around it, it's just going to get larger...and it's killing our people and we won't own***

***it...we don't even want to touch it, and that's going to be to the detriment of all of us."***

Silence and denial is also due to fear. By avoiding HIV-related issues, the fear of diagnosis and its consequences is also avoided. For individuals, it is difficult to think about HIV when it is presumed to be a death sentence. For communities, recognizing the existence of HIV-related issues threatens to destabilize the values, sense of belonging, and cultural support networks that many African and Caribbean people depend on to sustain them in Canada. These communities also fear that if they address HIV, they will unintentionally be supporting white society's stigmatization of and discrimination against them as carriers of the disease.

***"Fear holds me all the time [because I am HIV-positive]...I don't want to be judged, I don't want to be outcast. You know? That's really tough."***

HIV-positive individuals are fearful of disclosing their status to others, including family, because of the anticipated negative response. There is also a hesitation to seek new relationships or to be socially interactive. Due to the small size and close networks among some African and Caribbean communities in Toronto, there is concern that disclosure will result in ostracism. Hence, people living with HIV in these communities sometimes deny their status and/or choose not to disclose it to others. Some also gradually withdraw from their community or die without ever having disclosed their HIV status.

Fear of discrimination is particularly real for women contemplating disclosure. Heterosexual women tend to be more harshly judged for being HIV-positive than their male counterparts. Upon disclosing their HIV status to their partners, some women are rejected or abandoned, instead of being supported. Gay African or Caribbean men who are HIV-positive have concerns about disclosing their sexuality and status since it results in experiences of

discrimination, rejection, and ostracism on multiple levels. Fear also paralyzes some people into self-denial of their own or their partner's HIV-positive status, which can lead to delayed treatment and care.

### Alone in a new country: Trying to fit in

*"It's tough without your family. I have nobody...if something happened to me [because I'm HIV-positive], what would happen with my kid [since I have no other family in Canada to help me]?...It makes me feel like cry[ing] because I really love my family so much...I hope God will help me to bring them here to be with me."*

*"...I don't know why I told [my friend] my status...I made a very big mistake. Because she told everyone in the community...they know I'm HIV-positive and they talk bad about me...call me names."*

African and Caribbean people who are new immigrants in Canada often leave family in their countries of origin, in hopes of securing employment to support family members back home or sponsor them to immigrate to Canada. Alone in a new country, they usually seek comfort and belonging in their cultural communities in Canada. Some arrive HIV-positive, while others contract HIV in Canada. In either case, once an HIV diagnosis is made, there is a fear that revealing their HIV status to others could potentially undermine the networks they count on and/or negatively affect the well-being of their families back home by opening them up to scorn. Additionally, there is a concern that divulging an HIV-positive diagnosis can compromise the chance of securing legal residency status or sponsoring family members to come to Canada.

### Challenges of everyday life

On a daily basis, African and Caribbean people living in Toronto attempt to manage numerous challenges that affect their capability to deal with health-related issues, including HIV. These challenges, commonly referred to under the term, 'social determinants of health', are beyond their individual control and require large-scale

systemic and social change in order to see a corresponding change in health status. Some of these challenges include racism, discrimination, immigration issues, poverty, income/employment, appropriate housing, and social exclusion.

***"Especially for poor people like me, it's not easy. Life is tough plus [HIV] and it makes it very complicated to live day in, day out, you know?"***

Many African and Caribbean people in Toronto experience low socio-economic status, and so, survival is the top concern. When the majority of energy and time is spent seeking steady income and securing basic necessities (such as food, housing, and family care), health status is a much lower priority, unless it seriously affects the ability to survive.

***"We live with it every day. It's not just HIV...I'm Black...I'm a woman...I was a single mom...on social assistance. Right there I cover all the grounds for you."***

Compounding their disadvantaged socio-economic status, African and Caribbean people are also faced with stigma and discrimination based on stereotypes and prejudices. Through daily interactions, media portrayals, and government systems, they constantly experience discrimination based on their race, country of origin, language, accent, culture, religion, immigrant status, income level, education level, etc.

The experiences of African and Caribbean people in Toronto and their responses to HIV must always be recognized and addressed in these contexts.

### Accessing support services

In African and Caribbean communities in Toronto, the most commonly mentioned barrier to accessing HIV-related support services is the risk of being seen (i.e. 'found out') by someone from the community. This suggests that confidentiality and anonymity about one's HIV-positive status are

paramount and must be assured. AIDS service organizations often become an alternate community where HIV-positive persons can socialize, volunteer, and work, without fear of judgment or discrimination. HIV positive study participants were inclined to access services where the service providers are also of African or Caribbean background. Furthermore, receiving and providing peer support and seeing other people in similar situations brings hope for the future: “...the turn around point was when I went to the first discussion group with people like me [HIV-positive] and having the same fears and the same worries and it made me understand that I’m not alone.”

### Recommendations from the community

When asked for suggestions on how to address HIV-related stigma, discrimination, denial, and fear, African and Caribbean community members in Toronto, including

those living with HIV, provided the following recommendations:

- Increase public education in the communities about HIV (risk factors, methods of transmission, myths, stigma and discrimination);
- Increase education and practice of cultural awareness/sensitivity among providers of medical care and support services;
- Need for spokespeople & celebrities to promote condom use and HIV testing;
- Involve faith and community organizations in community mobilization;
- Address social determinants of health such as employment, affordable housing, poverty;
- Increase HIV-related services offered by and for African and Caribbean communities.

## Conclusion

*Addressing HIV/AIDS in African and Caribbean communities in Toronto and Canada requires strategies that include, yet go beyond, targeting individual behaviour change. There is a need for a broader community and organizational development strategy that will provide a supportive environment for prevention education, treatment, care, and support for those already infected. The development of a national strategy by African and Caribbean people to address HIV/AIDS within their own communities will enable an exchange of resources, strategies, and information that will increase public awareness and education in an effort to reduce the transmission and prevalence of HIV.*

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<sup>1</sup>In addition to the authors named on this fact sheet, the Stigma Study team included C. George, D. Willms, D. Taylor, R. Remis, S. Adebajo, F. McGee, A. Panoram, and E. Jacobet Wambayi. The research team was assisted by a Community Advisory Committee including V. Keyi, B. Nday wa Mbayo, S. Teclom and H. Teffera

<sup>2</sup>The full report is available as: Lawson, E., Gardezi, F., Calzavara, L., Husbands, W., Myers, T., Tharao, W. and the Stigma Study Team (2006) *HIV/AIDS Stigma, Denial, Fear and Discrimination: Experiences and Responses of People from African and Caribbean Communities in Toronto*. ACCHO and the HIV Social, Behavioural and Epidemiological Studies Unit, University of Toronto. The report is available from ACCHO, and online at [http://www.accho.ca/pdf/hiv\\_stigma\\_report.pdf](http://www.accho.ca/pdf/hiv_stigma_report.pdf). The study was funded by the Ontario HIV Treatment Network. This fact sheet was funded by a grant from the Levi Strauss Foundation. Neither funder is responsible for the content of this fact sheet.

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