

Charles Roy Memorial Lecture

Living, Learning and Serving
Responding to HIV/AIDS in Racialized Communities

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I want to thank the OHTN and the conference organizers for inviting me to deliver the inaugural Charles Roy Memorial Lecture at the OHTN Research Conference.

I feel honoured and grateful for the invitation, personally but also as a staff member at the AIDS Committee of Toronto.

Many of you know that Charles Roy was associated with the AIDS Committee of Toronto (ACT) for many years. At the time of Charles' death in 2002 he was Executive Director of ACT, a position he had held for six years.

I was hired at ACT during Charles' tenure as Executive Director, and I had the benefit and pleasure to begin my work at ACT under his direction.

Today I want to speak about our understandings and practices related to how race intervenes in the HIV epidemic, and speculate about how we might resolve the challenge that race seems to pose. I refer to race and racialized discourses as a challenge for a number of reasons.

First, social scientists have warned for some time that race, *per se*, has no analytical value, even though this is not how we experience society. Many of us have been *educated* to believe that race does not explain very much, but still this is not how we are *socialized*.

Second, despite personal commitments to live as though race does not explain much, we populate institutions that appear to have a life of their own beyond or independent of our personal commitments. Our institutions are capable of producing racist outcomes, despite the stated interests of the individuals who populate them.

Third, our experiences demonstrate that race matters even though we want to think and behave as though it doesn't.

I will address the situation of African/Black communities because these communities are particularly affected by the AIDS epidemic. I am also personally and professionally involved in those communities. Therefore, I will base my comments today on my everyday experiences as a Black Canadian originally from the Caribbean, my involvement in the institutional life of Black communities in Toronto over the last 18 years (including the Black Coalition for AIDS Prevention) while I worked in mainstream organizations, my observations from working in Africa, and my work with the African and Caribbean Council on HIV/AIDS in Ontario (ACCHO) over the past two years.

I have organized this lecture around the concept of "living and learning". The concept was one of Charles' major contributions to how we may think about and practice the work we do. I have taken some liberty with this concept, because I think that, as far as race is concerned, we also have some learning to do. For a

first hand read of Charles concept and argument, I refer you to his monograph titled *Living and Serving: Persons with HIV in the Canadian AIDS Movement*, which was published by the Canadian AIDS Society in 1995 and again in 1998.

In talking about race today, I've taken my cue from Margaret Wenté's column published in the *Globe and Mail* on August 15 this year during the International AIDS Conference in Toronto.¹ Ms Wenté implied that Black leaders have not exercised responsibility in the face of a serious AIDS epidemic affecting Black communities. She also implied that Canada's immigration system allows people from Africa to bring AIDS into Canada.

Many of us, me included, attempted to dispute rather hastily the claims made by Ms Wenté in her column. But I think that her column demands greater reflection than we offered at the time. To her credit she raised an issue (or set of issues) that we have been reluctant or afraid to address in our work on HIV/AIDS. To use a language that is fairly standard in reference to HIV/AIDS, we are infected and affected by race. Our silence about race shows only that we are reluctant to talk about it, not that it doesn't infect and affect our discourses and practices.

On a very straightforward level, and despite our personal attempts to avoid racialized interpretations of the HIV epidemic, many of us acknowledge that continental and diasporic Africans are disproportionately affected by HIV/AIDS.

- **Worldwide**, 64% of the 39 million people infected with HIV are in Africa. Sub-Saharan Africa and the Caribbean are currently the only world regions where HIV is endemic.²
- **In Canada**, people from Africa and the Caribbean represent just 2.5% of the population, but account for between 7% - 10% of people infected with HIV and 6% - 12% of new infections.³
- Here **in Ontario**, in 2004 approximately 14% of people living with HIV are from sub-Saharan Africa or the Caribbean. Moreover, the number of African and Caribbean people infected with HIV has increased by over 80% since the late 1990s.⁴
- In the **USA**, by the end of the 1990s, African Americans were 13% of the US population but comprised over half of new infections.⁵

¹ Wenté, M. (2006) A few down-home truths about HIV/AIDS in Canada. *Globe and Mail*, Aug. 15.

² UNAIDS (2006). *2006 Report on the Global AIDS Epidemic: Executive Summary*.

³ *HIV in Canada Among Persons from Countries where HIV is Endemic* (December 2005). HIV/AIDS Epi Update. Centre for Infectious Disease Prevention and Control. Public Health Agency of Canada.

⁴ Remis, R., C. Swantee, L. Schiedel, M. Merid and J. Liu (2006). *Report on HIV/AIDS in Ontario 2004*. Ontario HIV Epidemiological Monitoring Unit.

⁵ Centers for Disease Control and Prevention (CDC) (2005). Trends in HIV/AIDS diagnoses – 33 states, 2001-2004. *MMWR* 54, 1149-1153.

- In the **UK** in 2004 among people aged 16 - 44, it was estimated that 4.4% of the Black African population and 0.3% of Black Caribbean population were HIV positive, compared to 0.07% of the White population and 0.03% of the Asian population.⁶

What do we make of these data? How do we understand or explain this pattern? How does our understanding or interpretation of the pattern inform (or not) our response to HIV? Are we capable or willing to critically examine how we live and what we learn in order to improve our capacity to serve?

Conventional wisdom and even informed opinion equate Africa with AIDS and death. Nowadays, many Canadians know little else about Africa other than there is a huge AIDS epidemic. And in some quarters this epidemic appears to confirm a long-standing stereotype that continental and diasporic Africans are promiscuous. The women are easy, submissive or suffering; or, more recently in North America, they emasculate Black men. Black men, on the other hand, are violent, sexually aggressive, over-sexed, and irresponsible.

This general sentiment is not new in western thought. There is a long and sorry history of interpreting Africa through the lens of darkness, ignorance, decay and confusion. Within this frame of reference, the AIDS epidemic among continental and diasporic Africans would be consistent with their moral and material degradation.

However, AIDS has introduced some new perspectives on traditional stereotypes of Africa, Africans and people of African descent.

First, for many people the AIDS epidemic gives credibility to long-standing prejudices, namely, Africans and people of African descent lack self control; they do not seem to understand that actions have consequences; and African men, and Black men in general, are predators who have no respect for African/Black women.

Second, there is a view that AIDS is a peculiarly African/Black phenomenon – i.e., it originated in Africa, and Africans and Haitians then unleashed it on unsuspecting western (white) populations. Though we no longer debate this issue openly, some still hold on to the view that African people are wedded to outmoded and pre-modern behaviours, beliefs and customs that expose them to disease and disaster.

Third, in the popular media and even among so-called experts, it is common to ridicule African leaders and leaders in diasporic communities for an alleged lack

⁶ UK Collaborative Group for HIV and STI Surveillance (2005). *HIV and Sexually Transmitted Infections in the United Kingdom: 2005. Part 4 – Black and Minority Ethnic Populations*. www.hpa.org.uk/publications/2005/hiv_sti_2005/bme.htm.

See also UK HIV/AIDS FAQs. AVERT (www.avert.org/aidsfags.htm).

of leadership. The standard view of African and Black leaders that emerges in the regular media and even among Western experts is that they are and have been grossly irresponsible, incompetent and negligent, bordering on genocidal – they failed to act in the face of a massive epidemic that has decimated populations in Africa and the African diaspora in North America.

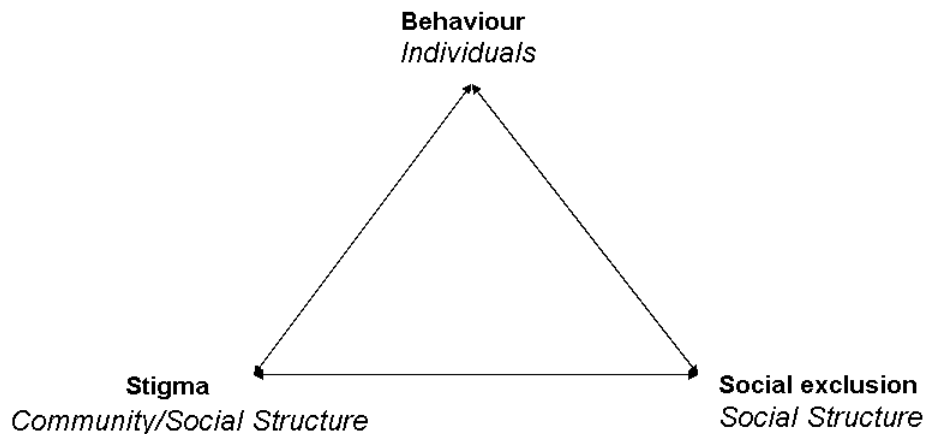
These opinions about Africans and people of African descent have practical ramifications for the work we do in Canada. In the supposedly non-racial world of health and social service organizations (which includes community-based ASOs), Black people are constructed as clients or supplicants, and their organizations are viewed as naturally weak and deficient. We (i.e., Black people) simply aspire to or demand a status that we are not qualified to hold. Consequently, Black people's attempts to exercise agency, or to be responsible and proactive about resolving challenges, are regularly viewed with suspicion, disinterest or even hostility by the organizations and institutions that are supposed to be working in everyone's best interest. We talk a lot about multiculturalism, but rarely about how decisions render Black people invisible.

Regarding HIV/AIDS in Africa, Canadians are fed a steady diet about the “human tragedy” of HIV in Africa – for example, how many people are infected, how rapidly the epidemic is spreading, the social dislocation and consequences attributed to the epidemic, and so on.

However, we seldom acknowledge that by the time HIV/AIDS became a public health issue in various parts of Africa, most African countries did not have the resources to respond effectively. By the early to mid-1980s, public health systems in many African countries had been seriously compromised by the structural adjustment policies of the IMF, foreign debt and corruption. Very little money was available to maintain health infrastructures. In short, many African countries were poised for a public health disaster.

As we struggle to get ahead of the epidemic, we ought to pause and consider a few crucial questions, such as: How do we move beyond the status quo? What considerations should inform our response to HIV/AIDS among Black/African diasporic communities in Canada? I will propose three levels of understanding and engagement that are instrumental in responding to the HIV among African and Caribbean communities in Canada (refer to Fig. 1).

Figure 1.
Understanding HIV in Black/African/Caribbean Communities in Canada



The *first* level of understanding and engagement addresses behaviours. Obviously, African and Caribbean people are having unprotected sex. We also know that many people are unaware of their HIV status because they've never been tested.

The immediate reasons for unprotected sex are rooted in cultural norms and attitudinal factors, in addition to insufficient knowledge of safer sex practices and testing options, and denial that HIV is an issue of concern. Some people also exempt themselves from safer sex based on misconceived understandings of risk that appear to them as factual and rational given their prevalence in African and Caribbean communities here.

Many of these issues are addressed in the *HIV Prevention Guidelines and Manual for African and Caribbean communities in Canada*, a resource developed by ACCHO for service providers working with African and Caribbean communities.⁷

As discussed more extensively in the Guidelines, gender relations in African and Caribbean communities is an example of how cultural norms and attitudinal factors limit safer sex decision-making among African and Caribbean women. African and Caribbean women, like women in other cultures, are generally socialized to be subordinate to the men in their lives. As a result, African and

⁷ *HIV Prevention Guidelines and Manual: A Tool for Service Providers Serving African and African Caribbean Communities in Canada* (2006). Toronto: African and Caribbean Council on HIV/AIDS in Ontario and Women's Health in Women's Hands Community Health Centre.

Caribbean women may be unable or unwilling to negotiate safer sex with their male partners, lest they be perceived as too aggressive or promiscuous. Women may be putting their long term relationship at risk, or sometimes even risk their physical safety, if they insist that their boyfriend or husband should use condoms.

Among African and Caribbean communities in Canada, the notion that only gay men, or “bullers” and “batty bwoys” get HIV is an example of the type of reasoning that may lead some people to exempt themselves from safer sex. If HIV is peculiar to gay men, then women are not at risk of HIV; neither are our brothers or sons who have sex with other men but claim to be heterosexual. Though we know this kind of belief to be untrue, its circulation within communities appears to make it rational in the eyes of community members.

These apparently rational understandings feed into stigmatizing beliefs about HIV/AIDS that impede people’s willingness and ability to get tested and to access programs and services that are available.

This brings me to the issue of Stigma, which has a pervasive community-wide presence, and which represents the second level of understanding and engagement that is instrumental in addressing the racialized pattern of HIV occurrence.

Many people seem to understand stigma as something that is peculiar to HIV. The stigma that we observe and experience in relation to HIV is rooted in commonly held views of how people understand themselves in relation to others. Thus, the stigmatizing traits that one set of people ascribe to others really constitute an ideology of discrimination.

In Caribbean communities, as in other communities, homophobia shapes our response to HIV as a disease, and our response to people who are (or are thought to be) infected with HIV. HIV belongs to batty men, who are responsible for bringing this thing into our Caribbean communities.

Sexism, or gender relations more generally, also shapes the response to HIV among African and Caribbean communities. There is a common point of view that HIV is associated with loose or immoral behaviour, but quite often this is something that is more likely to be attributed to women than men. In addition, as I mentioned earlier, women who insist on safer sex with their male partners or husbands are likely to attract suspicion and sometimes violence because they are assumed to be loose or have transgressed their subordinate role.

We also have to acknowledge that racism is the source of a collective stigma that others attach to Black Canadians. This predates AIDS; it is a recurring theme in the encounter between Black people and White people over several centuries. Black bodies have been a source of peculiar interest among White populations, and this now informs how Black people are perceived in the era of HIV/AIDS.

So then, in a society in which AIDS is seen as another pathology of Black people, and where there is a history of viewing Black bodies as carriers of disease, which Black person or community would want to step forward and talk about HIV? What kind of courage does it take for a Black man or woman to present for services at mainstream community-based organizations without an assurance that those organizations are not infected by the negative stereotypes of Black people, or that they are interested and capable of engaging Black communities in any substantive way? Black people will ask, quite understandably, how can I trust you?

This raises the *third* level of understanding and engagement that is necessary for addressing HIV in racialized Black communities. This is really a comment on how our society is structured. Black people in Canada are economically disadvantaged and marginalized, they suffer social exclusion which increases their vulnerability to HIV. Communities that are affected in this way often lack the resources and social capital that allow people to make life-enhancing choices. In communities beset by high unemployment, low incomes, and insufficient access to the institutions that shape our lives and livelihoods, HIV will occupy a subordinate rank on the list of individual and community concerns. The risk of HIV infection becomes a theoretical possibility, while real life revolves around finding adequate employment, income and so on.

Most of the time, our discussions of racism in Canada boil down to posing and trying to answer the question of whether racism still exists in this country. But we usually limit our interpretation of racism to individual acts of prejudice and discrimination. Of course, individual acts must be part of this discourse. But what is lacking from our discourse is really serious consideration of how systemic forces and institutional practices reproduce racist outcomes, whether or not these outcomes were intentional.

Since the early 1980s, it has been shown over and over that ethnic and racial groups are rewarded differently in the Canadian labour market, even when they do not differ in some of the standard measures of human capital.⁸ In other words, after controlling for age, education, gender, immigration status and other characteristics, certain racialized groups experience lower levels of reward than others. All other things being equal, Black Canadians and some other racialized groups earn significantly less income than other ethno-racial groups of western European origin, and also less than the national average. In any ranking of ethno-racial groups by income, all other things being equal, Black Canadians are ranked close to the bottom.

Racial discrimination reproduces the outcomes that I just outlined, and underpins the relative disadvantage that Black Canadians experience. And the state is complicit reproducing our racialized hierarchy.

⁸ see Mensah, Joseph (2002). *Black Canadians*. Halifax: Fernwood Publishing.

These racialized outcomes have a cumulative impact. What I'm saying is that the disadvantage that people experience likely diminishes their ability and capacity to accumulate wealth and social capital, which in turn will likely affect their children's life chances.

Wealth refers to ownership and control of resources, and confers or advances the class status or privilege of our children. Research in the US has shown that the control and disbursement of wealth, perhaps more so than income, is a notable legacy and consequence of racial discrimination that helps to underwrite continued racial inequality.

I will refer to US data to illustrate my point about wealth.⁹ In the USA, in 1999, White families had substantially higher net worth than Black families - \$81,000 compared to just \$8,000 for Black families.

But it is when we examine inheritances that we get a good grasp about the cumulative and generational impact of inequality. Inheritance contributed significantly to net worth among Whites, but made no contribution to the net worth of Black families. Studies in the 1990s indicate that one-quarter of White American families received an inheritance on the death of a parent, compared to just 5% of Black families. Moreover, the average dollar value of inheritances to White families was substantially larger than the inheritances received by Black families, and these differences are predicted to increase over the lifespan of the baby-boom generation.

Given the racial disparities that we know exist in Canada, it is not surprising that people from racialized communities are twice as likely to be poor as other Canadians, and racialized communities tend to be over-represented in poor neighbourhoods.¹⁰

The three sets of issues that I've just outlined describe individual, community and systemic factors that affect the health and health-related decision-making of African and Caribbean people in Canada. There are not discrete elements from which we can pick and choose when we think about how to respond to HIV/AIDS among Black Canadians. For example, we may know that certain behaviours (e.g., unprotected sex) put people at risk of HIV, but any intervention to promote behaviour change must be informed by an understanding of peoples' reasoning processes, and cultural and structural forces that predispose people to risky behaviours. Likewise, unless we restrict our understanding of stigma to mere name calling, we must understand the sources of stigma in community life and the wider social structure.

⁹ These data are discussed in Shapiro, Thomas (2004). *The Hidden Cost of Being African American: How Wealth Perpetuates Inequality*. New York: Oxford University Press.

¹⁰ Galabuzi, Grace-Edward (2006). *Canada's Economic Apartheid: Social Exclusion of Racialized Groups in the New Century*. Toronto: Canadian Scholars Press.

If we are serious about the work we do, we do not have the luxury of addressing one set or level of issues and neglecting the other two. What I'm suggesting is that amongst us, there must be some understanding of how our work fits together to address the three layers of understanding and response.

As a starting point, the concept of civic engagement provides a guiding principle for framing our understanding of and response to HIV/AIDS in Canadian Black communities. Charles Roy's work on living and serving was, in my opinion, a case for civic engagement.

I interpret civic engagement as a process that includes two elements of understanding and acting.

First, civic engagement implies that we are, or become, connected with and involved in the communities that we serve. There is a moral principal here, namely that we are making ourselves and our communities better off because of this involvement. Therefore, I would also argue that this connection and involvement should take place within the context of building a movement or mobilizing communities to achieve certain ends.

Second, civic engagement implies that we engage governments and institutions on behalf of our communities. So we must intervene in the public policy agenda in support of, or on behalf of our communities. But we also have to work on or with institutions to ensure that institutional policy recognizes, supports, and advances the citizenship, in a broad sense, of our communities and the individuals associated with them.

So, to state in clear and simple terms, we cannot respond to HIV/AIDS in Black and other racialized communities without engaging those communities in substantive ways about the principles and content of the response. This is the basis of my claims about civic engagement.

This is not the place to talk about the content of the response to HIV/AIDS. But it is an excellent forum for talking about the conceptual framework for moving forward.

Catherine Campbell, writing about South Africa, has conceptualized HIV prevention as a community initiative which requires communities, first of all, to "take ownership" of the disease.¹¹ By this she means that communities engage themselves to normalize behaviours that enhance the health of those communities and their members. This in turn suggests that communities are mobilized to create and sustain attitudes and environments that enable and support improved sexual health.

¹¹ Campbell, Catherine (2003). *'Letting Them Die': Why HIV/AIDS Programs Fail*. Oxford: International African Institute and James Currey.

Our task, therefore, is to assist communities in fashioning perspectives and systems that enhance the response to HIV/AIDS – this includes new perspectives on sexuality, gender, anti-racism, and so on. It requires a critical understanding of the structural issues that affect our lives. Without this critical understanding, we revert to gossip, prejudice and stereotype masquerading as informed understanding. We will not be able to move forward.

For example, we have some real work to do in relation to masculinity among Black men in Canada. bell hooks has suggested that social exclusion prevents many Black men from fulfilling a basic requirement of manhood in a patriarchal society – Black men have a hard time providing for their families as men are expected to do, because of poverty, unemployment and so on.¹² Yet, Black men continue to aspire to this patriarchal notion of responsible manhood. This generalization does not necessarily apply to all Black men, but our observations suggest that there is a great deal of truth to it.

Since Black men do not wield the kind of power that normally defines men or manhood in our patriarchal society, they express their patriarchy mainly at the sexual level. As Black men, our power resides almost exclusively in domination over Black women and Black families.

For the last few centuries of our existence on this continent (i.e., North America), Black men have suffered under the stereotype that our bodies are dangerous. More recently, we have capitulated to this stereotype by evolving a concept and practice of sexualized manhood that is dangerous to Black communities. Too many Black men appear to have adopted for themselves a masculinity that subverts our communities.

The challenge for HIV prevention among Black men in Canada is to construct a masculinity that involves what bell hooks has called “healthy erotic agency” or “redemptive sexuality”.

On the whole, we all need to transform or overthrow the understandings, interpretations and practices that undermine the struggle for justice and limit our response to HIV/AIDS. However, this is not possible without communities and individuals achieving a critical understanding of themselves and their place in the wider society. Our responses to HIV/AIDS are more likely to succeed if we acknowledge and understand our identities, the reality of social exclusion, and relationships of power and privilege in our communities and in the wider society.

Over the past few years I have noticed a change in some quarters. ACCHO has managed to secure the support and goodwill of a few important institutions (such as the OHTN and the AIDS Bureau of the Ministry of Health), and we have forged ahead and delivered on some important initiatives. Still, as in the past,

¹² hooks, bell (2004). *We Real Cool: Black Men and Masculinity*. New York: Routledge.

too many institutions and people in important decision-making roles remain steeped in the old prejudices and stereotypes about Black people.

The critical understanding that I have spoken about is not just a job for Black or other racialized communities. All of us have to take the time and effort to understand how we are located with respect to the communities we serve. None of us can work effectively with racialized communities if we take these tasks and the communities for granted. We must be respectful. We cannot serve without learning.

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