

**SUMMARY REPORT  
OF THE COMMUNITY FORUM  
“FOR US, BY US, ABOUT US”:**

**AN OPPORTUNITY FOR AFRICAN AND CARIBBEAN COMMUNITIES TO ADDRESS  
THE ISSUE OF HIV/AIDS RELATED STIGMA AND DENIAL**

November 3<sup>rd</sup>, 2001

Toronto, Ontario

Prepared by the  
HIV Endemic Task Force (HETF)

For more copies of this summary report, the complete report or other documents on HIV/AIDS, contact the:

Canadian HIV/AIDS Clearinghouse  
400-1565 Carling Avenue  
Ottawa, ON K1Z 8R1  
Tel: 877-999-7740  
Fax: 613-725-1205  
E-mail: [aidssida@cpha.ca](mailto:aidssida@cpha.ca)  
[www.clearinghouse.cpha.ca](http://www.clearinghouse.cpha.ca)

This document and the complete report are also available on the Internet at:  
[www.phs.utoronto.ca/](http://www.phs.utoronto.ca/) - see "Links"

For more information on the HIV Endemic Task Force please contact:

Ms. Esther Tharao  
Women's Health In Women's Hands Community Health Centre  
2 Carlton Street, Suite 500  
Toronto, ON M5B 1J3  
Tel: 416-593-7655, ext. 226  
Fax: 416-593-5867  
Email: [esther@whiwh.com](mailto:esther@whiwh.com)

Mr. Darnace Torou  
Africans in Partnership Against AIDS  
517 College Street, Suite 338  
Toronto, ON M6G 4A2  
Tel: 416-924-5256  
Fax: 416-924-6575  
Email: [apaa@on.aibn.com](mailto:apaa@on.aibn.com)  
[darnace@hotmail.com](mailto:darnace@hotmail.com)

Ms. Floydeen Charles-Fridal  
Youth Clinical Services Inc.  
3451 A Weston Road  
Weston, ON M9M 2V9  
Tel: 416-742-2514, ext. 240  
Fax: 416-742-5855  
Email: [Floydeen@youthclinicalservices.org](mailto:Floydeen@youthclinicalservices.org)

This document is also available in French under the title: *POINTS SAILLANTS DE LA TRIBUNE COMMUNAUTAIRE « C'EST NOTRE TOUR » : UNE OCCASION POUR LES COMMUNAUTÉS AFRICAINES ET CARIBÉENNES DE S'ATTAQUER À LA STIGMATISATION ET AU DÉNI ASSOCIÉS AU VIH/SIDA*

## **INTRODUCTION**

The “For Us, By Us, About Us” Community Forum was organized by the HIV Endemic Task Force (HETF), an ad hoc working group of community agencies, researchers and government representatives that have come together to develop a Strategy to address issues related to HIV and AIDS among people from HIV-Endemic Countries. See Appendix One for a list of current HETF members.

The purpose of the forum was:

- ? to begin to voice issues related to HIV/AIDS stigma and denial within our communities of people of African and Caribbean descent, and to begin to develop ways to address these issues;
- ? to provide an opportunity to dialogue with each other on how we can move forward in addressing HIV/AIDS in our communities of people of African and Caribbean descent – how we can begin to help ourselves; and
- ? to try to focus on what is realistic, and to look at strategies and implementation.

The day began with inspiring presentations from Musa Njoko of South Africa, Michael Fox of Bermuda, and Rhonda from Toronto followed by brief question and answer sessions. Next a brief overview of the history and current work of the HETF was presented and then a summary of the results of a situation report on the Epidemiology of HIV Infection Among Persons From HIV-Endemic Countries in Ontario conducted by Dr. Robert Remis. In the afternoon participants had an open-forum discussion on the issue of HIV/AIDS stigma and denial and their effects on people’s lives and their communities.

The Summary Report can only capture some of the highlights of the day. The attached Complete Report provides a detailed record of the information presented and the richness of the discussions that were held.

### ***“Do Not Be Afraid and Be of Good Courage”***

This was Musa Njoko’s message to participants. Musa is a dynamic, young black woman, a motivational speaker, singer, and is HIV positive. She has worked with different government departments and various national and international agencies. Musa was one of the first women to disclose her HIV positive status in South Africa. She has been living positively and openly with HIV for the past 6 years.

The following are some highlights from her inspiring presentation.

*“We need to break the silence around AIDS and AIDS related issues. The key to conquering HIV is to break the silence.”*

HIV prevalence is high in Black communities in Africa and all other Black communities outside Africa. You may be a minority where you are but it is likely that the prevalence of HIV is high. Do not put your head down in the sand.

Look at the next person and take a moment to look at yourself. What makes you think that you are not infected or affected by HIV? HIV is not interested in your race, in your social status or your sexual orientation.

South Africa is well known for its success in conquering apartheid. It took the community to accept and acknowledge the problem, to refuse to accept it, and to begin to mobilize. We need to acknowledge the problem, accept that people living with HIV/AIDS have value in their lives, and work together to conquer HIV.

Some people feel that we shouldn't say HIV is high in Black communities because we will be targeted. But our own people are dying in silence and pain when there are things that can be done to help. We don't have time to put it under the blanket anymore.

*“I am the face of hope, I am the face of love, I am the face of life – I am not the face of AIDS. I expect to be treated with respect and dignity based on who I am, not based on my HIV status.”*

### **“I HAVE HIV BUT HIV DOES NOT HAVE ME ”**

*“Never in my 41 years have I stood in front of an audience and said I have HIV – I will do it today. I have HIV but HIV does not have me.”* Michael Fox of Bermuda began his presentation with this powerful statement. Michael is a musician and entertainer, and the Director and Administrator of the Allan Vincent Smith Foundation (a community-based AIDS Service Organization in Bermuda). He is an elected member of the Board of Caribbean Regional Network for People Living with HIV/AIDS (CRN) and was appointed to the UNAIDS Caribbean Task Force in June 1999. The Bermuda Department of Public Health has offered Michael the challenge of spearheading the development of a National AIDS Programme for Bermuda.

*“HIV is not about being promiscuous, it's not about prostitution, it's not about being an injection drug user (IDU), it's not about being gay, it is about you and me.”*

To be effective in HIV/AIDS work you need to get into the pot and be part of the stew, you need to deal with all components – education, prevention, care, treatment and support.

The reality of HIV/AIDS in the Caribbean is that people living with HIV/AIDS face isolation and discrimination and may be refused treatment.

*“Each of us has a part to play, we need to visit people living with HIV/AIDS, touch them, help them and support them. This can play a great part in removing the stigma of HIV and AIDS.”*

Michael’s presentation sparked discussion among participants. Some of the key points included:

- ? The Caribbean communities are small and everyone knows everyone, they are also very religious. We know each other and we don’t want people at home to know – the stigma has also immigrated.
- ? HIV is a test about your past, not only your future, it is about a lot of other silences – silences about being gay, about sex, etc.
- ? Face isolation in Jamaica as a gay man and isolation in Canada as a Black man; negative attitudes toward homosexuality and racism contribute to low self-esteem and negative self-identity; addressing gay rights and homophobia needs to be a key part of any strategy to deal with HIV & AIDS in our communities.

### **“HIV IS HERE AND IT’S NOT GOING ANYWHERE.”**

Rhonda, a woman living with HIV/AIDS in Toronto, concluded her presentation with this simple truth. She is the mother of three children and has been HIV+ for seven years.

I came to Canada on my own from Grenada to pursue a career in dancing. All I knew about HIV when I left Grenada was that people in Trinidad were being diagnosed with AIDS and it was a gay man’s disease. I was a woman and I had lived with the same guy for years so it never crossed my mind that I could be HIV+.

I used to want to go home to Grenada but my mother told me not to because she was worried about how I would be treated at home.

The Community Health Centres are providing an important service, they treat immigrants and refugees who don’t have health insurance and they have educated themselves about HIV/AIDS and services and organizations that exist.

God gives me strength and my kids do too. Friends who stick with you are also key. *“HIV woke me up a bit, it was a reality check. I have lots of goals, no one is going to keep me down.”*

## **HISTORY OF THE HIV ENDEMIC TASK FORCE (HETF): RETRACING THE FOOTSTEPS**

Esther Tharao, a Health Promotion Worker at Women’s Health In Women’s Hands Community Health Centre and a founding member of the HIV Endemic Task Force (HETF), provided a brief overview of the history of the HETF.

HIV is a very difficult issue as many feel it will compound the stigma that already exists due to racism. But the stigma and denial about HIV result in people being diagnosed late in the disease process. In some cases children are the first in a family to be diagnosed and by then one or both parents are very ill – *“people are not taking advantage of testing and early care and treatment”*.

We need to discuss how to support each other in positive ways around HIV/AIDS, *“we need to break the silence”*. That is what the HETF is trying to do.

In the mid 90’s service providers noted an increase in the number of people from African and Caribbean communities being diagnosed with HIV and seeking HIV/AIDS care and support services. A need for statistics to back-up the trends that service providers were seeing was identified.

In 1998, the groups came together to form what was then called the HIV Endemic Working Group. The organizations involved at the time included: African Community Health Education Services (ACHES), Africans in Partnership Against AIDS (APAA), Black Coalition for AIDS Prevention (Black CAP), Centre for Infectious Diseases Prevention & Control (formerly LCDC) of Health Canada and the AIDS Bureau, Ontario Ministry of Health and Long Term Care.

The Working Group decided that it needed a clear picture of the status of the HIV/AIDS epidemic among people from the African and Caribbean communities before it could decide where to go next. Dr. Robert Remis was hired to pull together all HIV/AIDS cases from various databases and provide an estimate of the status of the epidemic within the African and Caribbean communities in Ontario. The Remis report, entitled *The HIV/AIDS Epidemic Among Persons From HIV-Endemic Countries in Ontario, 1981-98: A Situation Report*, was released in November 1999.

The Remis report verified the trends front-service workers were seeing and established the need for a Strategy to address the issue. The Working Group invited other organizations working with African and Caribbean communities to begin the work of drafting a Strategy. Rexdale Community Health Centre, Centre médicosocial communautaire (CMSC), Youth Clinical Services, Women’s Health In Women’s Hands (WHIWH), Health Promotion and Protection Branch (Ontario Region) of Health Canada, and Toronto Public Health joined and the Working Group was re-named the HIV Endemic Task Force (HETF).

The Task Force has gathered information and input for the Strategy from a range of sources including: telephone interviews with selected service providers, researchers,

advocates and non-governmental organizations (NGOs) working with people from HIV Endemic Countries; and a mail out survey consultation to a wide range of service providers and community groups. The suggestions and recommendations from this Community Forum will also provide important input into Strategy.

### *Questions & Discussion*

Esther’s presentation sparked discussion among participants. Some of the key points included:

- ? In order for us to come out and talk about HIV/AIDS, we need to understand why we are not talking about it – need to acknowledge the denial that exists.
- ? We are already stigmatized with or without the data, with or without HIV we already face racism; there are a lot of positive benefits from getting the data, it isn’t better for us to keep silent while people continue to die.
- ? The African and Caribbean communities do not access the services that are already available; people are often only diagnosed once they are very sick, we need to get people testing earlier so they can take advantage of care, treatment and support services and/or prevention strategies.
- ? Need to raise awareness and prevention efforts – “this type of forum needs to go into the communities and the schools.”

## **THE EPIDEMIOLOGY OF HIV INFECTION AMONG PERSONS FROM HIV-ENDEMIC COUNTRIES IN ONTARIO**

Dr. Robert Remis, Department of Public Health Sciences, University of Toronto, presented some of the key findings of the Situation Report. What follows is a brief summary, a more detailed overview appears in the body of the complete Forum Report and Appendix Two contains a complete copy of the slides he presented.

### *Definitions*

HIV-Endemic:

- ? high prevalence of HIV infection in the general population (generally greater than 0.8% but may reach 20% or higher); **and**
- ? heterosexual contact is the most important mode of transmission.

Prevalence: the proportion of a population that is affected by a disease.

Incidence: the rate of new infections of a disease.

*Study’s Mandate*

- ? to describe population born in HIV-endemic countries stratified by region of residence and country of origin; and
- ? to characterize incidence and prevalence of HIV infection among persons from HIV-endemic countries.

*Interpretation of Results*

- ? Estimates are based on modeling, therefore estimates are not precise but are in the plausible range.
- ? Also, the data used often had to be adjusted, adding additional uncertainty.
- ? Level of uncertainty is not known exactly, but is probably about 30%.

*HIV prevalence in 1998*

Caribbean	1,491
African	855
Total	2,346

Within the Caribbean: Four countries account for 87% of HIV infections

Jamaica	544	(36%)
Guyana	311	(21%)
Trinidad	295	(20%)
Haiti	142	(10%)

Within Africa: Five countries account for 72% of HIV infections

Ethiopia	158	(19%)
Somalia	138	(16%)
S. Africa	133	(16%)
Uganda	96	(11%)
Kenya	91	(11%)

*Summary of Findings*

- ? Modeling exercise produced plausible estimates of 2,350 HIV-infected persons (Caribbean 1,500; sub-Saharan Africa 850)
- ? HIV infection among persons from HIV-endemic countries is:
  - lower than in persons living in country of origin
  - lower than among MSM and IDU
  - higher than other heterosexual persons in Ontario
- ? The number of infections is increasing substantially year over year

- ? Estimates must be considered an hypothesis: observational studies are required to confirm findings particularly prevalence studies

### *Questions & Discussion*

The presentation sparked a number of questions and a lively discussion. Some of the key points included:

Is there a way to identify where the infection took place? Most people assume people were infected in their countries of origin but that may not be true.

- The HIV prevalence of people who arrive in Canada is lower than the HIV prevalence in their countries of origin but higher than heterosexual Canadians.
- There is no reason to expect transmission of HIV to stop when people arrive in Canada. The rates of prevalence are higher within communities of people of African and Caribbean descent. This will increase transmission of HIV, not necessarily only due to high risk behaviours but also because there are larger numbers of people infected with HIV within those communities.

How are people classified in the data?

- Data used is not race-specific, it is by “country of birth”.
- Statistics are not perfect, there may be some biases in the data due to misclassification from immigration data which records last country of residence (e.g. a number of Somali people resided in Kenya before coming to Canada), however misclassification would not produce systemic bias and thus the trend and patterns in the data are still relevant.

There are significant differences among countries in Africa, Francophone Africans and Haitians face particular issues – why are they not represented in the data?

- There were not enough cases from Francophone Africa to be able to construct an accurate model.

Thank you for the study, it is high time to admit that the rates are much higher than in the general Ontario population. The reality is that people in our communities tend not to get tested.

Will further studies based on race-based data be done?

- This is one of the issues that the HETF is trying to address. There are a lot of mixed feelings within the African and Caribbean communities and outside these communities about the need for, and the problems with gathering race-specific data.

## **WRAP-UP OF MORNING SESSION**

The Master of Ceremonies thanked all of the speakers, particularly the international guests.

Participants were invited to network with each other and to visit the display tables during lunch. They were also encouraged to share any comments or concerns they had about the day with members of the HETF. See Appendix Two for an overview of forum participants.

## **AFTERNOON SESSION**

The afternoon Master of Ceremonies, Mr. Patrick Soje, echoed the appreciation to the morning’s speakers for their courage and their important message.

The original plan was to have small group discussions to answer the following questions:

- What is HIV/AIDS stigma and denial?
- How is HIV/AIDS stigma and denial affecting your community?
- What are the best ways to deal with HIV/AIDS stigma and denial in African and Caribbean communities in Toronto/Canada?

However, participants decided to remain in the large group with the exception of the youth who opted to have their own small group discussion with a report back to the larger group. French translation/interpretation was provided in the large group.

The following is a summary of the large group discussion.

### *What is HIV/AIDS stigma and denial?*

- ? Belief that it is a disease of white people, gay men, prostitutes...
- ? Fear of further marginalization and discrimination
- ? Communication about sex / sexuality in families lacking (taboos)
- ? Lack of knowledge about testing
- ? Fear of being exposed in community (during testing)
- ? Safe sex not romantic
- ? Belief that AIDS is a death sentence, it’s better not to know your status

*How is HIV/AIDS stigma and denial affecting your community?*

- ? People are not learning about HIV/AIDS, it is difficult to mobilize the community
- ? There is a lack of pressure by community on funding agencies for services, research/cures, etc
- ? Religious leaders not providing leadership
- ? Psycho-social issues - homophobia / sexuality - shame and stigma silences the gay community
- ? Increase in orphans, disruption of childrens lives, reduction in quality of life
- ? Disclosure is not occurring, people are not accessing testing and treatment which increases disease progression and infection rates
- ? Fear of disclosure has resulted in separation of families and violence toward women, forcing women to go to shelters - displacement of families – poverty

*What are the best ways to deal with HIV/AIDS stigma and denial in African and Caribbean communities in Toronto/Canada?*

- ? Address lack of funding from government
- ? Collaboration / partnerships / networks
- ? Increase the frequency of community forums and take them into the communities
- ? Increase African / Caribbean representation in service provision
- ? Need to discuss our differences as African People
- ? More education and awareness to be integrated in the school curriculum - use of condoms etc, particularly in Catholic schools
- ? Promote opportunities for the communities to talk about homosexuality and hear and learn about the impact on all of us of our attitudes about homosexuality
- ? Task force needs to be representative of communities identified in the study

*Report of Youth Small Group Discussion*

- ? Learn about HIV from gym class / videos; get it from sleeping around, transfusion, needles / sharing, rubbing blood together, breast milk
- ? AIDS is associated with immoral behaviour
- ? Afraid to tell parents because of stigma
- ? Need to provide more education and get tested

## **NEXT STEPS/WHERE DO WE GO FROM HERE**

The HETF will:

- ? send participants a detailed report of the Community Forum;
- ? use the suggestions from today to develop focus groups in specific communities to gather additional information, particularly from those who are isolated such as African and Caribbean people living with HIV/AIDS;
- ? study the feasibility of bringing this type of Community Forum into various communities;
- ? continue to develop a process for broadening the membership in the HETF; and
- ? send participants a copy of the draft Strategic Plan developed by the HETF.

Participants encouraged the HETF to:

- ? broaden the membership of the HETF as soon as possible to include members from other parts of the province especially Ottawa, and to include representation from all the affected African and Caribbean communities;
- ? recognize that the group setting is an important stimulus and do more Community Forums; and
- ? work with funders to ensure effective monitoring of funds (i.e. that funding given to organizations actually supports effective programming).

An apology was extended for the time limits placed on the afternoon discussion - the facility had imposed a strict closing time for the event.

On behalf of the HETF, Floydeen Charles-Fridal thanked everyone for participating in the Community Forum.

**Appendix One:  
Members of the HIV Endemic Task Force (HETF)**

<b>Members of the HIV Endemic Task Force (HETF)</b> As of June 24 <sup>th</sup> , 2002	
Mr. Tony Caines Toronto Public Health 175 Memorial Park Avenue Toronto, ON M4J 4Y6	Tel: 416-338-0916 Fax: 416-338-0921 Email: <a href="mailto:tcaines@city.toronto.on.ca">tcaines@city.toronto.on.ca</a>
Ms. Floydeen Charles-Fridal Youth Clinical Services Inc. 3451 A Weston Road Weston, ON M9M 2V9	Tel: 416-742-2514, ext. 240 Fax: 416-742-5855 Email: <a href="mailto:Floydeen@youthclinicalservices.org">Floydeen@youthclinicalservices.org</a>
Ms. Suzanne Dufour Former HIV Project Coordinator (CMSC) 30 Sunrise Avenue, #401 North York, ON M4A 2R3	Tel: 416-752-5683 Fax: 416-752-6505 Email: <a href="mailto:suzanne.dufour@sympatico.ca">suzanne.dufour@sympatico.ca</a>
Ms. Rosemary Erskine Actions Now Coaching 106-109 Erskine Avenue Toronto, ON M4P 1Y5	Tel: 416-544-0621  Email: <a href="mailto:r.erskin@sympatico.ca">r.erskin@sympatico.ca</a>
Ms. Camille Griffith Black Coalition for AIDS Prevention 110 Spadina Ave., Suite 207 Toronto, ON M5V 2K4	Tel: 416-977-9955, ext. 30 Fax: 416-977-2325 Email: <a href="mailto:admin@black-cap.com">admin@black-cap.com</a>
Mr. Henry Koo HPPB Ontario Region Health Canada 4 <sup>th</sup> Floor, 25 St. Clair Avenue East Toronto, ON M4T 1M2	Tel: 416-954-5018 Fax: 416-973-0009 Email: <a href="mailto:Henry_Koo@hc-sc.gc.ca">Henry_Koo@hc-sc.gc.ca</a>
Mr. Frank McGee AIDS Bureau Ontario Ministry of Health 4 <sup>th</sup> Floor, 5700 Yonge Street North York, ON M2M 4K5	Tel: 416-327-8797 Fax: 416-327-9388 Email: <a href="mailto:frank.mcgee@moh.gov.on.ca">frank.mcgee@moh.gov.on.ca</a>
Mr. David Mordecai	Email: <a href="mailto:dymordecai@yahoo.com">dymordecai@yahoo.com</a>

**Appendix One:  
Members of the HIV Endemic Task Force (HETF)**

<b>Members of the HIV Endemic Task Force (HETF)</b> As of June 24 <sup>th</sup> , 2002	
Dr. Robert Remis Dept. of Public Health Sciences University of Toronto McMurrich Bldg., 4 <sup>th</sup> Floor 12 Queen's Park Crescent West Toronto, ON M5S 1A8	Tel: 416-946-3250 Fax: 416-978-8299 Email: <a href="mailto:rs.remis@utoronto.ca">rs.remis@utoronto.ca</a>
Ms. Senait Teclom African Community Health Services 76 Gerrard Street East, 2 <sup>nd</sup> Floor Toronto ON M5B 1G6	Tel: 416-591-7600, ext. 23 Fax: 416-591-7317 Email: <a href="mailto:zest71@hotmail.com">zest71@hotmail.com</a>
Ms. Esther Tharao Women's Health In Women's Hands Community Health Centre 2 Carlton Street, Suite 500 Toronto, ON M5B 1J3	Tel: 416-593-7655, ext. 226 Fax: 416-593-5867 Email: <a href="mailto:esther@whiwh.com">esther@whiwh.com</a>
Ms. Jasmine Thibault Centre médico-social communautaire de Toronto 22 College Street Toronto, ON M5G 1K3	Tel: 416-922-2672 ext. 245 Fax: 416-922-6624 Email: <a href="mailto:jasmine@cmsctoronto.org">jasmine@cmsctoronto.org</a>
Mr. Darnace Torou Africans in Partnership Against AIDS 517 College Street, Suite 338 Toronto, ON M6G 4A2	Tel: 416-924-5256 Fax: 416-924-6575 Email: <a href="mailto:apaa@on.aibn.com">apaa@on.aibn.com</a> <a href="mailto:darnace@hotmail.com">darnace@hotmail.com</a>

**Appendix Two: Overview of “By Us, For Us, About Us”  
Participants**

---

Names of individual forum participants are not provided in order to maintain the confidentiality of people living with HIV/AIDS who were in attendance. Participants are classified according to the types of organizations they were affiliated with, if any.

The following table shows the number of participants who registered for the forum and their organizational affiliation.

<b>Type of Organization</b>	<b>Number of participants</b>
1. AIDS Service Organizations	15
2. Broader Health Services (CHCs, etc)	23
3. Social Service Agencies	16
4. Settlement Service Agencies	10
5. Students	5
6. Youth	3
7. Government	3
8. Religious organizations	3
Estimate of non-registered participants	20
Total	98

Please note that 7 of the registered participants self identified as French speaking. It is also important to note that a significant number of participants, particularly youth did not complete a registration form.

The table below illustrates the sources through which participants heard about the

<b>Source of Forum information</b>	<b>Number of people</b>
1. Network	2
2. Press release	2
3. Flyer	2
4. Mailing to organization	5
5. Newspaper	2
6. Affiliated organization	50
7. Friend/family	6
8. Internet	2
9. Word of mouth	2
Total	73

forum.

