

HETF: Report on Phase Two of Community Consultation

April, 2003
Prepared for HIV Endemic Task Force
Prepared by Consultant Team:
Amita Handa, Ph.D
Astier Negash

For more copies of this report 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
www.clearinghouse.cpha.ca

This document is also available on the Internet at:

www.phs.utoronto.ca/ - see "Links"

For more information on the HIV Endemic Task Force or the African and Caribbean Council on HIV/AIDS in Ontario please contact:

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
darnace@hotmail.com

EXECUTIVE SUMMARY

The HIV Endemic Task Force (HETF) came together as a result of initiatives on behalf of Toronto based AIDS Service Organizations (ASO's) and researchers at the University of Toronto to address issues related to HIV for communities in Ontario from endemic regions. In the past, HETF's work has included epidemiological research conducted by Dr. Robert Remis in 1998 aimed at providing a comprehensive perspective on the incidence and prevalence of HIV infections in Ontario among populations from endemic regions (see Appendix 1 for Executive Summary). The findings of this research indicated increasing rates of HIV infection among people of African and Caribbean descent (PACD).

In an effort to address some of the issues affecting this population, HETF has carried out two phases of community consultations for the purposes of developing a strategic plan. The results of Phase one were used to develop a draft strategic plan. This report highlights the findings of Phase Two of consultation, which focused primarily on input from people living with HIV/AIDS (PHA's) and service providers for the purposes of identifying priorities issues confronting PHA's of African and Caribbean Descent. It also included the participation of at risk youth. This report is meant to aid in the development of the final strategic plan.

Findings highlight stigma, racism, employment, immigration, funding, training of health care professionals and access to housing, financial assistance and treatment as key issues affecting PHA's. As a result of these findings, the consultant team has put forth 10 recommendations to the HIV Endemic Task Force. We recommend that HETF play a leading advocacy role with respect to PHA's access to immigration, housing, financial assistance and consistent employment. We also recommend that HETF recognize stigma as a key issue affect PHA's from African and Caribbean descent and be involved in the development and dissemination of educational strategies aimed at alleviating different forms of stigma. Recommendations also advise HETF to consider the amalgamation of ethno-specific HIV/AIDS related services and programs. Findings also highlight the need to shift the focus on the allocation of funding for the purposes of needs assessment to an emphasis on program development and service delivery for PHA's. PHA's and service providers expressed their frustration over initiatives that continually document the needs of HIV+ individuals without adequate follow through.

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2. Moderators Guide for Interviews
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BACKGROUND AND DESCRIPTION OF THE STUDY

The HIV Endemic Task Force (HETF) came together as a result of initiatives on behalf of Toronto based AIDS Service Organizations (ASO's) and researchers at the University of Toronto to address issues related to HIV for communities in Ontario from endemic regions.¹ Its founding members included community based service providers, such as the Black Coalition for AIDS Prevention (Black CAP), Africans in Partnership Against AIDS (APAA), African Community Health Services (ACHES), Women's Health in Women's Hands, Centre Medico-Social Communautaire, Youth Clinical Service Inc. and Rexdale Community Health Centre. HETF has been closely affiliated with representatives from the municipal, provincial and federal government, such as the City of Toronto Public Health Department, Ontario Ministry of Health and Long Term Care AIDS Bureau, and Health Canada Population and Public Health Branch (Ontario Region).

HETF's work to date has included the following:

- ◆ 1) *Situation Report: "The HIV/AIDS Epidemic Among Persons From HIV-Endemic Countries in Ontario, Update to 2000", Dr. R.S. Remis*
- ◆ 2) Phase One: Community Consultations and the "For Us by US" Community Forum resulting in "*Draft Strategy to Address Issues Related to HIV Faced by People in Ontario From Countries Where HIV is Endemic*"
- ◆ 3) Phase Two: Community Consultation for the purposes of finalizing the strategic Plan

¹ Endemic is an epidemiological term that refers to regions or populations where there is a high prevalence of HIV infection amongst the general population. HETF has been concerned with the regions of Sub Saharan Africa and the Caribbean which have been classed as HIV endemic. Endemic areas are identified as those in which the incidence of HIV infection is 1% or higher. Research These regions are generally understood as comprising Sub-Saharan Africa (Angola, Botswana, Burundi, Cameroon, Cape Verde, Central African Republic, Chad, Congo, Djibouti, Equatorial Guinea, Ethiopia, Gabon, Gambia, Ghana, Guinea, Guinea-Bissau, Ivory Coast, Kenya, Lesotho Liberia, Malawi, Mali, Mauritania, Mozambique, Namibia, Niger, Nigeria, Rwanda, Sao Tome Senegal, Sierra Leone, Somalia, South Africa, Sudan, Swaziland, Tanzania, Togo, Uganda, Upper Volta, Western Sahara, Zaire, Zambia, Zimbabwe) and the Caribbean.(Antigua, Bahamas, Barbados, Cayman Islands, Dominica, Dominican Republic, French Guyana, Haiti, Jamaica, Martinique, Montserrat, Netherlands Antilles, Nevis-Anguilla, Lucia, St. Vincent, Surinam, Trinidad-Tobago, Turks and Caicos Islands, UK Virgin Islands, US Virgin Islands) (Dr. Remis, 1999).

In the past, HETF's work has included epidemiological research conducted by Dr. Robert Remis in 1998 aimed at providing a comprehensive perspective on the incidence and prevalence of HIV infections in Ontario among populations from endemic regions (see Appendix 1). The findings of this research indicated increasing rates of HIV infection among people of African and Caribbean descent (PACD). In an effort to address some of the issues affecting this population, HETF has carried out two phases of community consultations for the purposes of developing a strategic plan. In Phase One, HETF sought feedback through telephone interviews with service providers, researchers, community members and community based organizations, conducted a questionnaire mail out to various parts of the African and Caribbean communities, including service providers, mainstream general health service organizations, and held the "*For Us By Us*" *Community Form, 2001*. The results of Phase One were used to develop a Draft Strategic Plan.² In Phase Two, consultants carried out further consultations with parts of the community through individual interviews with at risk youth, focus groups and individual interviews with PHA's (including French speaking PHA's) and service providers in Toronto, Kitchener and Ottawa (see Table 1 in Methodology Section). The emphasis in this phase of research has been on interviewing PHA's and those who can speak to issues confronting PHA's. This report outlines the key findings of Phase Two. The report includes research methodology and findings from PHA interviews, service provider interviews, and interviews with youth. Based on the information gathered, we have outlined a number of recommendations that emerged from the participants that may be used to direct the final Strategic Plan.

² The Draft Strategy to Address Issues Related to HIV Faced by People in Ontario From Countries where HIV is Endemic is attached as Appendix 1.

PROJECT TEAM

The Project Team consisted of two people. While both team members consulted on all aspects of the project together, one member focused primarily on networking, recruitment and individual interviews in Toronto with PHA's and service providers, while the other focused on recruitment of participants in Ottawa, focus group facilitation, analysis and report writing. A French consultant was hired for individual phone interviews with French speaking PHA's residing in Ottawa. The project team met regularly with HETF's Community Working Group (CWG) throughout the process of the consultations. The CWG was made up of HETF's member groups and served as an unofficial steering/advisory committee for this project.

METHODOLOGY

While Dr. Remis report, in part set out to quantify the incidence and prevalence of HIV/AIDS, Phase Two has focused on exploring the complexity of issues affecting PHA's and understanding the meaning and impact of HIV/AIDS in the community. The purpose of this phase of consultation then is to identify the issues and barriers related to HIV/AIDS with respect to people of African and Caribbean descent in Ontario. The consultant team used a qualitative approach to explore concerns relating to HIV/AIDS in these communities. Four groups of people were approached for this consultation: women and men of African heritage; women and men of Caribbean heritage; English and French speaking service providers in Toronto and Ottawa; and at risk Caribbean youth. Toward this end, we conducted focus groups and/or individual interviews with PHA's, English and French speaking service providers and youth.

Table 1: Phase Two Consultation

- 1 Focus group with English and French Speaking Service Providers (Ottawa), n=7
- 1 written feedback from service provider in Ottawa, n=1
- 1 Focus Group with Service Providers (Toronto), n=3
- 7 Individual key informant interview with Service Providers (Toronto), n=7
- 3 Individual key informant interviews with French Speaking PHA's (Ottawa), n=3
- 8 Individual interviews with male and female PHA's (Toronto), n=8
- 1 Focus Group with African HIV+ women (Toronto), n=4
- 1 Focus Group with Caribbean HIV+ women (Toronto), n=2
- 5 Individual key informant interviews with at risk Caribbean youth (Toronto), n=5

Recruitment of Participants

Three sections of the population were approached for this consultation: Service providers, PHA's and at-risk Caribbean youth (non-PHA's). A total number of 40 people participated in this consultation. PHA's were recruited through newspaper ads, flyers posted at sexual health clinics and ASO's, and referrals from ASO's and ethno-specific AIDS related organizations. Service providers at hospitals, ASO's, including faith leaders involved in HIV related work, ethno-specific agencies, health centers, and community agencies at large were contacted to participate in this consultation. Youth were contacted through Eva's Phoenix, a shelter for homeless at-risk youth.

While the team attempted to consult with all parts of the community equally, this proved to be difficult. We interviewed more PHA women than men, more African PHA's than Caribbean PHA's and a greater number of African service providers. In order to solicit further consultation from the Caribbean community, the team decided to add individual interviews with Caribbean youth and an interview with the front line support worker at Black CAP.

Focus group interviews were taped with one note taker present and ranged from 2-3 hours in length. Facilitation and note taking was conducted by the consultant team members themselves. Individual interviews were most often done over the phone and lasted approximately between 30 minutes to 1.5 hours. Of the 18 service providers interviewed, seven were from endemic regions, 3 of which were Caribbean and 4 of African descent. One Ottawa based service provider was unable to attend the focus group and therefore provided written feedback on the Draft Strategic Plan . The length of time service providers worked in their organizations ranged from between 6 months to 12 years. Table 2 contains an outline of overall participants:

Table 2: Breakdown of Overall Participants

<i>Breakdown of overall participants</i>			
Ethnicity	Category	Gender	Number of participants
African	PHA's	2 male/10 Female	12
	Service Providers	4 Female	4
Caribbean	PHA's	2 male/3 Female	5
	Service Providers	2 Female/1 Male	3
	Youth	3 male/2 Female	5
Other	Service Providers	1 male/10 Female	11
			40 total participants

Recruitment and Profile of Service Providers

A broad range of service providers were approached for this consultation, including health care providers, religious leaders, AIDS service organizations (ASO's), community health centres, frontline workers, hospital staff, including doctors and nurses, social workers, counselors and immigration lawyers. Most of the service providers who responded to a call out for focus group participation tended to be frontline workers working in the HIV related field. Service provider profiles are outlined in Table 3.

A total of 18 service providers were consulted in Toronto and Ottawa for this phase of the project through focus group participation and key informant interviews. Three service providers participated in the focus group in Toronto. Being overworked, “tasked-forced to death” and funding cut backs were cited as reasons for low focus group participation among service providers in Toronto. Individual interviews were also conducted as a means to broaden service provider participation in this consultation. An additional 7 individual interviews were conducted with service providers in Toronto. Service providers worked in HIV based settings, ethno-specific agencies, general health care delivery and community agencies at large.³

Seven service providers participated in Ottawa's focus group discussion. These included those working in HIV clinics in hospital-based settings, service providers in general health services as well as the project officer of the Multicultural Health Team.

All service provider interviews were done face to face. The majority of service providers were front line workers and worked in the capacity of front line work as nurse, social worker, counselor, caseworker or psychotherapist. Of a total of 18 service providers who participated in this consultation either as a focus group participant or as a key informant, 7 were of African or Caribbean descent. All, but two service providers were either given an advanced copy of the *Draft Strategy* or provided with a copy during the focus group discussion or interview. Even

though the *Draft Strategy* was provided, service providers provided few specific or substantive comments on the document. In many cases, service providers had not read the *Draft Strategy* in advance. In some instances, the consultant team asked the participating members to take some time during the focus group session and read through the strategy. However, even in this case, the document did not generate much discussion. There was a sense that service providers were over-worked and had little time to read the strategy given their priority focus on front-line work and services. The majority of the focus group time was spent on identifying key issues relating to HIV/AIDS for PACD.

Table 3. Breakdown of Service Providers

<i>Service Provider Profiles</i>	
<u>Position</u>	<u>Type of Service</u>
Social Worker	Rape Crisis Centre
Psychotherapist	HIV Hospital Clinic
Project/Program Coordinator	Women's Shelter
Counselor	Ethno-specific ASO
Researcher	Ethno-specific Community Organization
Support Worker	
Nurse	
Case Worker	

There was some discussion with the HETF, CWG about whether to include those working in HIV specific settings or those working in the general social services sector. The team decided to consult with both kinds of service providers. We included those working specifically in the area of HIV and those working with African and Caribbean PHA's for what they could tell us about the barriers and issues related to HIV health care. Also, due to issues of confidentiality, it was

³ Appendix 3 includes a list of participating organizations/service providers.

difficult to obtain access to PHA's. Service providers working directly with them were consulted as a means of accessing the experiences of PHA's and for their expertise and knowledge of HIV related issues. Those working in the general social services sector were also consulted to explore what kinds of links are being made between HIV and general health issues and how HIV is placed within the general health care agenda.

While there was an attempt to recruit a broad range of service providers, including religious leaders, a very small number of service providers who worked in non-HIV related health services responded. Of the broad range of individuals and organizations that were contacted for participation, only two who were not working directly in HIV related services responded and these two either had a special interest or personal investment in the issue. One was from a women's shelter in Toronto and the other was from a Rape Crisis Centre in Ottawa. This low participation of general health service providers was also confirmed by the attempt to involve CHC's in outlying areas of Toronto, such as Black Creek Community Health Centre. Despite the fact that this organization serves a large number of African and Caribbean clients, service providers at the site felt that HIV was not a significant issue among the population they serve and explained that they had few, if any HIV+ clients from these communities.

Recruitment and Profile of PHA's

PHA's in Toronto were recruited through advertisements in two community newspapers, one of which is a Black Caribbean newspaper (Share), the other a general community Newspaper (Now Magazine) which is popular among both the heterosexual and Les/bi/an, Gay, Transexual (LBGT) communities in downtown Toronto. PHA's were also recruited through flyers posted at Hassle Free Clinic, the Bay Centre for Birth Control, AIDS Committee of Toronto (ACT), ACHES and Voices of Positive Women.

Despite an extensive effort to outreach PHA's from African and Caribbean communities, particularly those who are new immigrants, newly diagnosed and accessing services outside the downtown Toronto core, most of the PHA's interviewed were part of existing PHA support groups. Two PHA's were recruited through flyers and newspaper ads, the rest were recruited through ASO's, such as Black CAP, APAA, ACHES, Voice of Positive Women and Teresa Group. Those who followed through with the interviews or focus group discussions were from the first three mentioned organizations.

Originally, due to issues of anonymity and confidentiality, we did not anticipate the possibility of focus group participation from PHA's. However, through discussions with ethno-specific AIDS organizations, we learned that there were some HIV+ women who would be willing to participate in focus groups. Due to stigma and racism, disclosure of HIV status is extremely difficult for most PACD. Most of the PHA's who responded to the call for focus group participation were part of existing support groups and were individuals for whom fear of disclosure with health professionals and researchers is not as much of an issue as it is for most PHA's. Even for the PHA's who participated in focus group discussions, stigma emerged as among the top most salient issues.

The barrier of disclosure was an ongoing challenge to recruitment, even more so in Ottawa and was therefore a limitation to acquiring a representative sample. While we were able to reach PHA's who may not be comfortable with disclosure by means of individual phone interviews, this study is limited by a lack of participation of those who may be greatly isolated. Though we attempted to reach both male and female PHA's, more HIV+ women responded to the recruitment process. Though it is beyond the scope of this study, at some point HETF may like to explore the cause for gender differences in research participation.

Another limitation of this study is the lack of participation of non-English and non-French speaking language groups. One reason for this is due to the fact that we recruited PHA's from

ethno-specific AIDS organizations (Toronto) or medical clinics (Ottawa). Because these participants were already accessing services in English or French, they were obviously fluent and comfortable enough in these languages to obtain services. The need for culturally sensitive and accurate language translation and interpretation was mentioned by service providers as an issue affecting PHA's. This issue has also been incorporated in the draft strategy and needs to be maintained as among the priorities of HIV/AIDS related services.

The consultant team found it very difficult to recruit PHA's in general. It was an added challenge, therefore, to obtain clients who have been newly diagnosed. Those who have been newly diagnosed are presented with a broad range of issues, such as health issues, shock, and immigration, which need their immediate attention and are therefore less likely to participate in a research study of this kind. Also, due to issues of disclosure, both PHA's and service providers explained that it takes a long period of time to convince and encourage PHA's to access systems of support that require networking with other PHA's, especially support groups. This is another reason as to why newly diagnosed clients are less likely to connect to a public study of this nature or disclose their status to interviewers with whom they have not developed a relationship of trust. Of the total PHA's that were interviewed, 4 were newly diagnosed.

For reasons of disclosure, PHA participation in Ottawa proved to be even more difficult. We were informed by a consultant team contracted by the AIDS committee of Ottawa to identify issues relating to HIV/AIDS with refugee and immigrant populations, that obtaining ethics approval for access to this population would be extremely difficult.⁴ For these reasons, we did not recruit participants through newspapers ads or posting flyers at health agencies in Ottawa. We did, however, obtain access to some PHA's through a case worker at St. Anne's Medical Centre. General feedback from service providers in the Ottawa focus group emphasized disclosure as an ongoing challenge to service delivery. Service providers explained that it had been very difficult

to establish support groups for PHA's in Ottawa due to the high need for anonymity and fear of disclosure. We, therefore, conducted over the phone interviews with French speaking PHA's in Ottawa.

In addition to PHA's from Ottawa who participated in this consultation, we interviewed two PHA's from Kitchener. Both of them, however, admitted to accessing services in downtown Toronto due to the lack of HIV/AIDS services in Kitchener. This study is limited by the lack of PHA consultation in other parts of Ontario, aside from Ottawa, Toronto and Kitchener. The lack of HIV specific services outside large metropolitan areas posed a challenge to reaching individuals from outlying regions.

All PHA's, whether focus group or individual interview participants were offered a Twenty dollar honorarium for their participation.

Due to issues of confidentiality, consultants obtained verbal consent from PHA's. Participants were explained the nature and purpose of the consultation and advised that they did not have to answer any questions they did not feel comfortable with and could end the interview at any time. Most PHA's were uncomfortable with signing their name on any print consent form. For obvious reasons, verbal agreement was obtained over written consent for over the phone interviews.

Many of the women had children, ranging between 1 to 8 children. At least three of the women interviewed had children who were HIV+. For women who were HIV+, childcare emerged as a priority concern and often limited their access to services. Some of the women had children who were HIV+ and therefore had additional care giving responsibilities.

Most of the PHA's included in this consultation were between the ages of 23 and 52 and all were of low socioeconomic status. Most of them were unemployed and on Ontario Disability Support Program (ODSP), 2 were students, 1 participant was working as a lab technician, another as part-time domestic help. Of the participants who disclosed information about their sexuality,

⁴ In their experience, they did not get access to PHA's from endemic regions because the Research Ethics Board from Public Health and Long

one identified as a gay male, the other a bisexual male, both of Caribbean descent. The countries of origin for PHA's consulted in this study included Kenya, Grenada, St. Vincent, Jamaica, Liberia, Zimbabwe, Congo, Burundi, Rwanda, Ethiopia, and Cameroon.

With respect to those who shared their immigration status, 5 were landed immigrants, 5 were refugee claimants or Conventional Refugees, 1 had a Minister's Permit, and 3 were Canadian Citizens. Immigration status greatly affected their level of healthcare, treatment, and access to housing. This will be discussed under the Immigration Section. |

Recruitment and Profile of Caribbean Youth

At risk Caribbean youth were included in the consultation for several reasons. The team wanted to obtain greater input on HIV/AIDS related issues from a Caribbean perspective and as well as data from different age sectors of the population. Through discussions with CWG, it was decided that it is important to consult not only with PHA's and service providers but general members of the African and Caribbean communities so as to get a sense of how parts of the community are thinking and responding to issues relating to HIV. In conjunction with the CWG, the team also identified the inclusion of marginalized sectors of the community as important. The team felt that at risk Caribbean youth could provide a unique perspective on attitudes and behaviors related to sexual health and HIV/AIDS. This perspective is significant to prevention education and outreach strategies.

The youth were recruited through a youth counselor at Eva's Phoenix which is a shelter for homeless at risk youth and is located in downtown Toronto. The youth ranged between 19-24 years of age. Of the five youth interviewed, 3 were young black men, two were women.⁵ The youth were from the Caribbean, primarily from Jamaica and Trinidad. They were living at Eva's Phoenix for various reasons. None of them had access to affordable housing, family or friends

Term Care Branch had demanded an extensive ethics review process due to the "highly vulnerable" nature of this population.

with whom they could stay with or feel comfortable staying with and some had been “in and out of the streets.” Most were involved in an employment program called Eva’s Initiative, which offers job training through internships and placements in areas such as skilled trade and computer programming. Topics such as impression of HIV/AIDS generally and in the West Indian community specifically, safe sex and condom use among peers and HIV testing were explored in these individual over the phone interviews with Youth. The interviews, on average lasted approximately between 20 minutes to 50 minutes in length.

Instrument Development

A moderators guide was developed for service providers, PHA’s, and youth.⁶ These questions were used as a guide to direct the general flow of interviews with participants and were open-ended questions. The questions explored participants’ impressions of HIV/AIDS, community beliefs, knowledge and access of services, personal experiences with HIV/AIDS issues, challenges and suggestions about HIV/AIDS issues in their community (Please see Appendix 2 for all participant questionnaires).

With PHA’s, we asked general demographic questions as well as questions exploring their experiences around being HIV+, service delivery and access. Through these interviews, PHA’s were able to identify barriers with respect to their access to health care. Focus group questions were modified somewhat from this format to suit a group interview.

Analysis Design

Thorough notes were taken for each interview. Facilitators’ notes and note takers’ notes were used as the basis of data for the focus groups. Tape records of focus groups were kept as a back

⁵ Because overall male participation was lower than female participation, the team actively recruited more Caribbean males than females for individual interviews. This was achieved through putting up notices in places that were more male-specific.

⁶ Interview questions are attached as Appendix 2.

up in the case of any confusion or needed elaboration but were not required. All notes were detailed and taken by the consultant team themselves. For interviews in French, a French consultant was hired who conducted the interviews, took notes and translated notes into English. Both team members contributed to the coding and analysis process. One of the consultant team members identified significant thematic areas, which were then used to construct a coding scheme. This was then cross-checked with the other consultant team member and modified as needed throughout the process when relevant. The themes involved general issues affecting PHA's, access to HIV related services and suggestions with respect to raising community awareness and education on HIV/AIDS and the improvement of service delivery. This report has separated youth from the findings of service providers and PHA's. Because service providers and PHA's spoke more specifically about identifying issues related to PHA's, these findings have been presented together. The findings from youth interviews, however, are provided in a separate section because youth spoke more directly to attitudes and behaviours related to sexual health and the issue of HIV testing.

FINDINGS

HIV/AIDS emerged as a significant concern for all the groups involved in this consultation – PHA's, youth and service providers. Youth spoke to issues, attitudes and behaviors relating to sexual health, prevention education and testing. Service providers and PHA's spoke about general issues affecting PHA's, the accessibility of health care services and issues pertaining to prevention education. Key issues that were identified by both PHA's and service providers are profiled in Table four. They include stigma, treatment and non-medical issues, such as immigration status, access to housing and employment.

Table 4, Key Issues

Key issues as identified by service providers and PHA's
Stigma
Racism
Immigration
Treatment
Housing
Funding
Financial Assistance
Education and Training of Health Care Professionals
Employment
Religion

PHA's and service providers identified stigma, racism, immigration, funding, access to treatment, training, education and access to adequate housing, financial assistance, religion and employment as key issues. General observations on the behalf of service providers suggested that there is an increasing number of people from endemic regions that are in need of HIV related services. Health professionals from Sunnybrook Hospital observed that they had been seeing more patients from endemic areas, especially women. At present, approximately 20% of their clients are from endemic regions and their projection is that this figure will grow. Toronto People with AIDS Foundation (PWA) also confirmed this increase in clientele. One service provider made a general observation about the decrease in HIV related information: *"In my experience, about three years ago, people were running and doing things about HIV/AIDS, but now it is given as if it is controlled and decreased."* The PHA focus group with HIV+ women echoed a similar concern observing that while the needs of PHA's from endemic regions are increasing, funding has decreased and a lot of essential programs have been cut. One PHA asked, *"I want to know if everyday new people are being infected, why is funding being cut. New clients are suffering so*

much. They don't have the same confidence and strength that some of the older clients have who are still living with HIV because a lot of the support systems have been cut."

Stigma and Racism

Stigma came up as a significant issue for all focus groups, including the focus group with PHA's and greatly affected access to services. It was identified as the cause of isolation and depression in many of the PHA's, and in some cases was related to substance use. The stigma of HIV/AIDS has to do with its association to all or any of the following: socially unacceptable groups of people and behavior, such as prostitution and promiscuity, homosexuality, drug addicts, being a curse from god. While these negative connotations can be said to be part of a general social stigma against AIDS, individuals from endemic countries are further marginalized due to issues of settlement and adjustment in Canadian society, cultural and linguistic barriers and the stereotypes associated with being an African or Caribbean PHA. Stigma is seen to play a significant role in contributing to the following:

- Isolation
- Depression
- Substance use
- Secrecy of HIV status
- Hesitation or denial of access to HIV related services
- Community gossip and ostracism

Attitudes about HIV/AIDS "back home" and here in the community played an important role with respect to stigma for most PHA's. Many PHA's still had strong ties to family back home. PHA's identified a greater association of hatred, ignorance and ostracism from their own community. In the African HIV+ women's focus group, there was some discussion around whether the context of Canada was better over the context of "back home." Some felt that there is greater access to treatment here and therefore the Canadian context is more encouraging. Though secrecy is a factor that affects the lives of PHA's everywhere, due to the connectedness of their own communities, the issue of gossip and the difficulty of keeping matters private, the need for

anonymity and confidentiality is paramount among PACD. However, others felt that *“back home there is more discussion of AIDS”* especially in regions where it is endemic. As one PHA described, *“people end up accepting you there because it is more of a reality...you have your family there. Those who ostracize you are not your family. Here people don’t play with your kids and you are in a foreign land. People don’t reject you back home because there is more knowledge about AIDS.”*

Some of the myths associated with AIDS are not as commonplace in endemic regions where people know that you cannot contract the illness by hugging or sharing a glass. In regions where HIV is endemic, people have first hand knowledge about the caretaking of PHA’s. As one woman explained, *“For new immigrants, it is harder. No Family members. Here one has to rely on the health care system to take care of you. Back home, it is the family and people and they have more hands on experience in dealing with AIDS.”*

Aside from the stigma related to “back home” racism and cultural discrimination were identified as factors contributing to the issue of stigma in Canada in several ways. Firstly, most participants felt that AIDS is over associated with African and Caribbean peoples. Participants identified relationships of power between dominant and immigrant communities, as contributing to this perception. Due to this prevailing stereotype, AIDS is seen as a result of African and Caribbean culture and attitudes rather than as resulting from a contagious epidemic. This perspective does not take into account issues of power, racism, poverty and limited access to resources, which play a significant role in the spread of HIV infection in endemic regions. As one community member commented, *“as an African person these days you can’t even afford to have a fever without people thinking you have AIDS.”* Marginalized already as immigrants and outsiders to dominant Canadian culture, PACD’s feel the added burden of constantly having to defend their cultural reputation and esteem. Racism is not only manifested in the challenges of settlement and adjustment. For Black people of African and Caribbean descent, there has been a

long history of marginalization and exclusion on the basis of race. This factor plays an important role in the perception of western research and medicine. It was found in some PHA interviews that western treatment, medication and service providers are often viewed with suspicion, both because of a long standing history of racism as well as ongoing mistreatment and discrimination.

The difficulty for PACD is that mainstream health and ASO's cannot always address needs and concerns in a culturally appropriate manner, while going for help in their own communities is fraught with the fear of gossip and ostracism. In both focus groups, there was some debate around whether having PACD's as service providers, front line workers and health professionals was an asset or barrier to access of services. In some cases it was seen as an asset because of the importance of having community representation from the community in mainstream health and ASO's. Often, a front line worker who is of African or Caribbean descent can relate to the cultural context and needs of clients who are of the same background. While at other times, it has adverse affects for those who fear community gossip and ostracism. As one service provider explained, the stigma of going to an AIDS organization is so high that "*even sexual health workers [and AIDS related service providers] are labeled with stigma [of having AIDS].*" A Caribbean woman, for example, refused to receive homecare because she believed that a lot of the staff were black and she might be found out.

For example one bisexual Caribbean male PHA explained, "*HIV/AIDS seems to be a gay white male funded program. It is dominated by them. As a result, there is not enough resources available for people of African and Caribbean descent and a lot of us don't feel comfortable going.*" In the interviews and focus groups, homosexuality was discussed both in terms of homophobia within the community and the difficulty of gay/lesbian PHA's. Also discussed was how the association of HIV as a homosexual disease creates a false sense of safety and misinformation. Homophobia within the community was identified as magnifying issues of stigma, confidentiality and access to services for LGBT. Because for endemic regions,

heterosexual contact is the primary mode of transmission it was also felt that endemic communities get lost within the parameters of MSM risk. PHA's also mentioned this as an issue in the focus group. They felt that there are a lot of well developed services for the gay PHA population, many of which they do not identify with.⁷

Stigma was identified as a significant barrier affecting access to services and was related to several issues, such as the fear of disclosure and the need for confidentiality and anonymity. The issue of confidentiality is considered so paramount that one service provider commented, *"it is sad that the stigma and issue of confidentiality is so high that there is self denial of services, people do not want to talk to service providers for fear of gossip...stigma overrides everything to the point where people are willing to risk their lives."* In the PHA African women's focus group, many women narrated the difficulty they experienced when having to access AIDS specific organizations. Some waited a great length of time to enter into conspicuous AIDS related organizations, like the AIDS Committee of Toronto (ACT). Some PHA's admitted to wearing disguises or circling the block until they were certain nobody was around.

Self image and community acceptance emerged as being very important for PHA's and some clients mentioned how difficult it was to even send a photo back home for the fear of relatives detecting any kind of illness or weight loss. Due to stigma and the resulting need for confidentiality, fear and secrecy significantly affects the lives of those who are HIV+. A male PHA explained that *"I can't be in a relationship because I don't want to tell nobody that I am HIV+. I have no friends, because I don't want to tell them that I am HIV+ but I feel like a liar if I don't. I don't get too close to anybody because I feel like a liar. I felt lonely, I started drinking alcohol, being lonely causes one to be unstable. I went for alcohol treatment but I feel like I am the only one [there] with HIV."* Here the participant explains how isolation, depression and

⁷ Please refer to the PHA focus group section for a more detailed explanation of this point.

substance abuse can be closely related to issues of stigma creating a vicious cycle of marginalization.

Isolation affected the majority of PHA's who were interviewed. Many of them had not disclosed their status to close friends or family members. The fear of being discovered as HIV+ was also a factor affecting access to housing, employment and immigration. One service provider recounted the experience of a PHA who had to wait one year for adequate housing, partially because she was afraid to disclose her HIV status. She with-held her HIV status from housing authorities despite the fact that a social worker had assured her that in this case her HIV status would speed up the process. Once she disclosed her status, she received housing with 2 months. Most who have landed immigrant status wanted to sponsor family and do not want to obtain sick benefits through employment insurance, the concern being that it will impact the immigration process. Also, because a lot of immigrants do not want to jeopardize their immigration status or process, they do not want to be tested. This is a factor that contributes to the spread of the virus.

A member of the service provider focus group in Toronto suggested that we look at stigma differently, that risk should not be divided into risk (unacceptable) and non risk (acceptable) *“but it is either you are living or dead. By removing groups, you may be able to take away stigma. I believe there are only two groups. The dead who are safe and the living who are at risk. The whole association of groups may be encouraging the issue of stigma, risk and denial.”* The discussion in the Toronto service provider's focus group explored how stigma can be related to issues of denial, especially when it defines AIDS as being an illness only affecting certain groups of people. It was explained that those coming from endemic regions may have a false sense of safety in the west: *“in the community, there are false beliefs regarding the safety of people because there is the association it only happens to prostitutes, intravenous drug users, hemophiliacs, or through blood transfusions – this is how it ends up being spread because of these false beliefs...[For] those migrating from Africa, because of the low incidence of AIDS here*

compared to their homeland, they feel they are not at risk.” Risk can be associated with certain groups in certain regions. Those having migrated to the west from an endemic region may associate AIDS in Toronto as a “homosexual” illness and thereby feel protected if they are heterosexual.

The focus group with service providers in Toronto put the stigma of AIDS in historical context with the reminder that 50 years ago cancer was also stigmatized and that now this has changed. It may be helpful to look at some of the education strategies that health promoters have used with respect to cancer and other terminal illnesses.

With respect to stigma and confidentiality as being concerns adding to the complexity of issues affecting PACD and access to services, an Ottawa based African service provider drew attention to the ways these “complexities” often become a scapegoat as to why issues do not get addressed or why this population is hard to reach. She suggested that issues of confidentiality might be blown out of proportion. She asked, *“can confidentiality ever be guaranteed, not just with HIV/AIDS but any issue that is stigmatized, such as rape, for example?”* Sometimes the high priority on confidentiality ends up reinforcing isolation, *“could it be that service providers are internalizing the issue of stigma and the high need for confidentiality rather than empowering clients to over come issues of stigma.”*

At the end of a three hour discussion in the African women’s PHA focus group on issues relevant to PHA’s, such as immigration, racism, housing, poverty, isolation, confidentiality, one woman reflected, *“ when you think about it, the solution to everything is that there be no stigma, not the stigma of racism or poverty or AIDS.”* Related to the last point about stigma in general, workshops on different kinds of stigma, HIV/AIDS being one of them, arose as a suggestion by Ottawa focus group with service providers. Other suggestions with respect to strategy planning included utilizing the settlement process as a point of education. Education to remove stigma in the form of workshops in the community was mentioned as a priority by service providers and

PHA's. This would be most effective if directed at community and religious leaders and school heads. Recruiting PHA's of African and Caribbean descent was identified by almost all interviewed, including youth, as a means to reduce stigma. Interviews with youth and focus group discussions suggested the use of media over print. Service providers felt that there was "too much dependence on written pamphlets" and that it was important to disseminate information about HIV in other mediums, including radio, video and music.

Because the fear of disclosure is so high, homecare was identified as an important vehicle to alleviating some of the barriers relating to service delivery. Homecare can be an alternative to public services and a means of assuring confidentiality, provided the health professionals are trained adequately.

Religion

Religion was identified as playing an important role with respect to stigma. It is a significant means of coping and was described as a source of comfort for many PHA's. One focus group participant explained that HIV "*could be considered a punishment from god.*" This was linked to notions of general health and disease as in "*there is no such idea of natural death in the African community, there is the idea that somebody cursed you.*" Aside from being linked to issues of stigma, religion was a source of comfort for many PHA's. One Caribbean HIV+ woman who had only been in the country for less than six months and went to church three times a week explained, "*I go to god, I look for healing... [one day] I am crying going into the church – the pastor said, 'what's wrong with you? I told him everything. He said, 'Oh my god, I am so sorry.' He sang one beautiful song and asked everybody in the church to stretch their hand over me – and explained that I had been going through so much.*" An African PHA said, "*God is good. I pray to god to pre-long my life until my children grow up.*" Another PHA commented on how she coped when she first learned that she was HIV+: "*I keep my faith. I believe in Jesus. So, I prayed.*"

Everyday I was praying. The scripture says if you call upon his [Jesus] name and you have faith, you will never be ashamed.” One of the HIV+ women interviewed explained it took some time before she was able to find a church and pastor who was supportive.

Sometimes the belief in god and spirituality was an obstacle to accessing treatment. For example, one of the interviews revealed how a belief in god contributed to a refusal of treatment. *“My husband said, ‘don’t worry about it, they think they know everything, but god knows more.’ He believed that god was the medicine and felt I was wasting my time [with treatment] until he became very ill and hospitalized. [At this point] he told me I should let the kids take the medicine.”*

Some service providers explained that they did not know how to manage clients who refused treatment on the grounds of religion. Some clients did not look to health care professionals for healing, information and treatment and chose instead to place their health in the “hands of god.” In order to alleviate some of these problems, it may be helpful to create a dialogue between service providers and clients on the role of religion and culture with respect to treatment. There is a need on the part of health care professionals to acknowledge and work with varying religious beliefs and cultural contexts.

Immigration

For new immigrants who are HIV+, the immigration process itself, such as access to adequate immigration information and legal advice as well as one’s immigration status, has a tremendous impact on PHA’s. Immigration was identified as related to a long list of issues. (Please see Table 5).

Table 5, Issues relating to Immigration

Issues relating to Immigration
<ul style="list-style-type: none">➤ Confusion➤ Lack of coordinated Immigration information➤ Access to drug treatment➤ Access to financial aid➤ Access to employment➤ Family segregation and separation➤ Lack of community advocacy on behalf of PHA's➤ Lack of HIV- specific legal expertise

Immigration status and the immigration process as a whole was an issue that greatly affected PHA's and was compounded by a host of settlement and adjustment issues. The case of one woman illustrates some of the difficulties facing PHA's. As somebody who came here on a six month vacation from the Caribbean she explained the confusion and anxiety she faced when while on holidays she discovered she was HIV+: She decided to go get tested when she found out her ex-husband died of AIDS:

I don't want to go back home, everybody knows me and my husband. He used to go and come. When he became HIV+, they called back home. Now they all know. It is like headline news in my country. It is not that anybody will kill me if I went home, but people are not educated about HIV, they are afraid to be around you. If you are working and the boss knows you are HIV+, he can fire you. The government can't protect you, there are no laws in place." ... I have six children, four of whom depend on me. I couldn't go to the funeral due to immigration reasons...I have put in my refugee claim but my hearing is not till next year. I can't work, I can't go back home, I am separated from my children and I have HIV.

PHA's complained about not knowing how to access the immigration system, not having enough information about the immigration process and having to deal with immigration matters while at

the same time tending to issues relating to their illness. Of paramount importance is the issue of HIV status and its effect on the immigration process. While according to law, HIV cannot be used as a means to discriminate against somebody seeking landed status, there is concern about how one's health affects the chances for securing landed status. One cannot apply for refugee status based on the fact that they are HIV+. One can apply under compassionate grounds arguing that s/he is gay and/or HIV+, for example, and will be persecuted back home or on the grounds of religious or political persecution, but the individual still has to prove that s/he will not be a burden on the health care system. The immigration process also presents challenges with respect to accessing secure employment. One service provider explained that *“as a refugee claimant, once you have submitted a letter of intent, then you receive a letter of acknowledgment which means you can apply for welfare, you are given a work permit. [But then] you don't have Canadian experience”* and you will find great difficulty in obtaining a job without Canadian work experience *“which is bullshit because how much Canada experience do you need in flipping hamburgers?”*

With respect to immigration and issues relating to sponsorship, one woman lamented on how her situation left her with no options with respect to family reunification. Her husband was a political prisoner back home and he along with her children were awaiting her sponsorship. However, once she reached here, she discovered that she was HIV+: *“You are here running away for your life and here when you reach Canada, your life is at stake with such strong sickness. I thought I left all problems back home...”* As an HIV+ individual who is a refugee claimant, she is unable to sponsor the rest of her family. With respect to family separation and immigration difficulties, another PHA explained, *“My dream is to bring a family member here so they could help me. I don't have anybody and when I die, my kids don't have anybody...My kids say you always say you have a mom and relatives, but nobody comes to visit us...If you were a white*

person, it would be much easier but Africa is a lost country.” Here, as is the case of many African and Caribbean PHA’s, her isolation is due to her HIV status as well as racism.

Service providers identified immigration as a great barrier to services, especially drug treatment. In this way, the immigration process favors individuals who are independently wealthy. One service provider described how the immigration process blocks access to participation in the Canada economy at many levels: *“It takes three months for them to process your claim, they will do a medical check and will find out if you are HIV+. They will not withdraw your application based on this fact but can find another reason.”* If an individual decided not to obtain immigration as a refugee claimant but instead apply under the point system, those who are uneducated will find it impossible to be successful because they will lack the adequate number of points needed.

Those who are awaiting a letter of acknowledgment of refugee claim do not have access to OHIP and therefore have to pay for their treatment. This letter can take up to six months. During this waiting period, they are not able to work legally and therefore often don’t have the income needed for medication and treatment. As one service provider explains, *“we try to get them on drug trials or through drug company/pharmaceuticals. It is harder to get them on long term treatment.”*

The issue of isolation and family cohesiveness was something that greatly affected PHA’s. As one woman said, *“I am not well and don’t have anybody. They should feel sorry and understand that I need somebody. There should be an organization that helps people bring people here even if they don’t have money...”* another PHA explained, *I need to be working to sponsor my family but then most of us have health issues.”* Most of the PHA’s we interviewed had migrated on their own and were worried about family members back home. Some were worried about who would look after their children once they died. Others, were separated from their children and were not in a position to sponsor them. Even those who had landed status, due to their illness were not able

to work consistently and therefore did not fit the monetary requirements necessary for sponsorship.

Immigration was also mentioned as a barrier affecting HIV testing. Individuals feared that their HIV status would affect their immigration status. The Toronto focus group explained that most people from the community were not accessing HIV testing services and usually found out about their positive status accidentally.

Service providers are becoming overloaded with dealing with immigration issues and often need to focus on medical issues. There is a strong need for individuals who are experts in HIV related information as it relates to the law. These experts should be connected to health centres and ASO's. It is also essential to have advocates working on implementing changes to the immigration process that alleviate some of the difficulties PHA's face with respect to the immigration process. With respect to the settlement process, one service provider said, *“education needs to start right here...we need to link HIV education and literature as part of the settlement process.”*

Employment

The issue of disclosure also affected PHA access to employment. Due to social stigma associated with being HIV+, PHA's often did not want to disclose their status to work place authorities. Non-disclosure, however, became problematic when they needed to take days off work due to their illness or had to worry about concealing their medication from other co-workers. PHA's feared that disclosing HIV status to prospective employers, however, drastically affected employment opportunities.

PHA's explained that due to their illness it was often difficult to work consistently. This of course greatly affected their socioeconomic status. All the HIV+ individuals we interviewed were on disability insurance or welfare and live on or below the poverty line. While the former was

considered to be better than welfare because *“they do not harass you all the time to find a job,”* eligibility requirements meant that PHA’s had to have a certain CD4 count and be on treatment in order to apply. This did not speak to the needs of many PHA’s whose ongoing illness meant that CD4 counts fluctuated and those, whom because of side effects sometimes decided to terminate their medication. As one PHA explained, *“we are not getting enough from disability and what we get is hand to mouth. Just enough for rent, we can’t buy clothes or food. People expect you go to food banks not realizing there is a cultural problem. People can’t eat all the foods...[there are canned things and people aren’t used to that and some don’t even know how to prepare these.”* The issue of employment and financial need affects all aspects of survival, including housing: *“How can I pay \$800 in rent when I’m receiving \$997 in [social assistance] that would mean I would be left with \$97. I don’t think it could be enough for me and my daughter, for food or any other bill.”*

Funding

There was agreement between the Toronto and Ottawa service provider focus groups with respect to the impact of funding for this HIV/AIDS service delivery. It was noted that HIV/AIDS has become a ghettoized issue by becoming the concern of AIDS organizations only. Government funding helps to divide these issues. Many of the small AIDS organizations, or ethno-specific agencies do not have funding to address these issues or the expertise to write grant proposals. The importance of collaboration was mentioned on a number of occasions as being important for many reasons, such as normalizing HIV, providing more cohesive services and funding. As one service provider explained, addressing this issue, *“when one organization addresses it, it is not acceptable, if many organizations address it, it is acceptable. Number is power!”*

Both service providers and PHA’s argued that the needs of endemic communities have been brought to light before – *“nothing comes of these task forces,” “we are tasked forced to death”*

and that *“the complexities of endemic communities have been brought up for the past ten years. This is frustrating service providers and government officials are not proactive enough.”* PHA’s echoed a similar concern. The Toronto African women’s focus group voiced their frustration over money spent on research studies and initiatives that continue to document the problem rather than allocating funds to program delivery and service. They also felt used by community agencies and researchers as “sources of information” alone rather than being an integral part of the process from beginning to end. While researchers and community “experts” get paid adequately for their time and information, most PHA’s only receive small honorariums for their knowledge and time.

The Ottawa focus group emphasized that the patchwork approach to services resulted in a lack of cohesiveness, *“ownership of issues”* and the lack of appropriate services. As one participant explained, *“With the patchwork approach, service providers are reactive to people showing up rather than planning – we cut people into pieces – woman go here, HIV over there, immigration over there.”* Funding had a large role to play in creating a patchwork approach to services. Cut backs were mentioned as a significant limitation affecting services. The following service provider explains how HIV/AIDS issues for PACD end up at the bottom of the funding list: *“as it is health is conceptualized in a generic way, subsumed under that is HIV and there is a battle for funding for general HIV services and then more specifically there is ethno-specific issues, that is how it gets lost somewhere amongst a pile of issues.”* Service providers felt that the issue of funding was closely associated with the notion of risk groups. MSM, it was felt is identified as high priority, while other populations are not seen in the same way. From a prevention education perspective, some participants felt that endemic communities should also be identified as high priority and as a potential increasing risk group.

PHA’s in Toronto also complained about the impact of funding cutbacks. In the African women’s focus group, women observed that a number of essential programs had been cut. Participants were upset and missed several programs, especially those offered by Black CAP,

such as the African Food Basket.” *“food was brought straight to your home and everything was fresh” and represented foods from African and Caribbean contexts.*” This service recognized the importance of confidentiality and was sensitive to African and Caribbean food habits and cuisine. Also important were other services affected by funding cuts like Black CAP’s “once a month Sunday lime.” The need for social outlets was described as being very important and most of the women spoke highly of PHA support groups.

With respect to the need for both social and educational programming, all the participants in the focus group, including individual interviews, spoke strongly about Black Cap’s retreat. Speaking about this year’s retreat where approximately 30 people attended, including PHA’s from the United States, a participant said, *“people were crying at the retreat...it was only two days, imagine if that happened twice a year...people were bawling, grown men.”* The retreat was described as an important outlet for sharing, support, venting, and meeting other people. While individuals were able to bond with others with similar experiences, it was also a place where they learned more about issues relevant to them, such as drug treatment and side effects.

Participants argued for the need for more funding for HIV/AIDS related services for people of African and Caribbean descent, including prevention education. It was felt that HETF could play a leading role in advocating for HIV/AIDS related funding. PHA’s identified the need for cohesive services as a priority. Many felt they had to access services at many different sites for the various issues that affected them, such as immigration, housing, financial assistance and treatment. With respect to the issue of “patchwork” funding and the dispersion of services, both PHA’s and services providers recommended that HIV related programs be amalgamated. As one PHA argued, *“if all organizations amalgamating like Black CAP, APAA, Aches...if organizations could work together, sometimes we get lost between all of them, we have to go to different places...this isn’t a dance party, this is life and death – you can’t look at differences between Africa and Caribbean communities [and be separate]. That is a non-HIV perspective. We need to*

come together and be strong; we don't have the luxury of being so scattered. Guys, we have been sleeping, let's way up!"

Focus group participants emphasized the need for support structures, such as the retreat organized by Black Cap and suggested that this service could greatly benefit PHA's if it could happen more frequently. In an individual interview, one PHA echoed the need for such social outlets by reminiscing on a drop in Centre in Montreal where *"you could just drop in, use the phone, have some coffee, and be exposed to different workshops, like arts and crafts."*

Education and Training

Several PHA's mentioned the need for training of general health care professionals. Many felt that their family doctors, home care nurses and other general health care providers did not have a basic and adequate understanding of HIV and its related issues. PHA's emphasized that family doctors know very little about HIV and it was difficult to have regular access to specialists. They also mentioned pharmacists as a target group for education. One PHA explained the embarrassment and humiliation she felt when the pharmacist at a local drug store made her repeat the name of her medication several times because he did not know what the medication was. Issues of confidentiality being paramount here, the client felt disturbed that others may be able to identify her as HIV positive. For example, one PHA described her frustration with the health care system because she had to get most of her information from the internet: *"Doctors only concentrate on CD4 and viral load. They don't talk about side effects. They don't talk side effects about the medication and the effect on the heart, liver... I feel comfortable talking to my doctor. If the doctor can just swallow the pills and can feel how you are feeling it can be better."*

A woman from the African PHA focus group had a similar experience when she explained that she was unable to be given an accurate description of her health and had to find out about HIV related issues on her own. One PHA viewed the health care system with skepticism and suspicion

when they breached her sense of confidentiality. The following excerpt explains not only the importance of confidentiality but also a lack of general knowledge on how HIV is spread: *“The Hospital system is very bad. They do things they shouldn’t be doing. They destroyed my whole life. The nurse told my neighbor that my husband died of AIDS when I told her not to. The nurse told the neighbour because she said she needs to know in order to protect her family [from HIV].”* She also narrates the story about her husband who left hospital care for home care because the nursing staff was making derogatory comments toward him. He ended up dying at home because he could not take the humiliation of the staff. When home care was called because her husband was in need of medical attention:

“home care said they would call Children’s Aid because my kids would go to school and give it to other kids and that the other children living at home would also get it. So I called the Social Worker at the hospital and she explained to the home care worker about the virus. After this, the homecare worker said I need help from Children’s AID to help with the kids. I said I don’t need any help, I have raised my kids all this time.”

Several service providers and PHA’s recognized the need for greater training for health care professionals with respect to basic HIV/AIDS information. Most PHA’s felt that service providers do not view all aspects of care as their responsibility. There were complaints about basic issues of respect and courtesy from staff and many explained that often the health care workers only came to help us “pop pills,” This is especially important for illnesses like HIV which are chronic in nature and require constant and continued contact with health care professionals. Because PHA’s are often in contact with many aspects of the health care system, from physiotherapy to Children’s AID and women’s shelters, PHA’s emphasized the need for greater HIV training among social service agencies. It was felt that most service providers did not have an adequate understanding of HIV/AIDS.

Many women complained about the lack of adequate child care facilities and the fragmentation of services for adults and children. Those who had children were constantly going to doctors appointments either for themselves or their children and often had to go to different

ends of the city. Mothers who are HIV+ are often in the position of needing childcare without being able to afford it.

PHA's felt that some health care professionals did not have a basic grasp on modes of HIV transmission. Cultural insensitivity was also mentioned as a barrier to adequate health care. Mainstream service providers we interviewed often relied on staff or clients from endemic communities as a source of information on cultural context. Relying on the former frequently means that if a frontline worker of African or Caribbean descent leaves the organization, it often reduces the capacity of the organization to delivery culturally appropriate services. Relying on clients for cultural sensitivity training often puts a burden on PHA's who already have a long list of issues they are struggling with. It is for these reasons that health care professionals, including doctors, nurses and home care workers need to be adequately trained on issues relating to HIV/AIDS and cultural sensitivity.

Youth

Interviews with youth explored attitudes and behaviors related to sexual health in general with a particular emphasis on HIV/AIDS. While they all described themselves as practicing safe sex, they reported that most of their peers did not always practice safe sex. All but one of the youth interviewed felt that did not have enough information about HIV and AIDS. Youth listed stigma and shame as amongst the issues that felt affected PHA's. While they all said that they worried about HIV/AIDS and that it was definitely a concern amongst their peers as well, it was not amongst their top ten list of worries. They named, survival, other black youth, cash, job, career advancement, education, providing a positive role model for younger members of the community, and "what are we going to do with our lives" as among their top ten priorities. The youth provided suggestions on HIV prevention and raising awareness in their community. Having

PHA’s from their community as role models involved in public speaking and educational workshops was mentioned as key to raising awareness among youth within the community.

General Impressions of HIV/AIDS and HIV Testing

The youth listed a number of variables which they felt affected their lack of knowledge about HIV as well as several reasons for low participation in HIV testing. (Please see table 6).

Table 6, Reasons for low HIV Testing Among Youth

Reasons for low HIV Testing rate Among Youth	
➤ Lack of Time	GENERAL
➤ Lack of Treatment for HIV	
➤ Fear of Health Care System	BOYS
➤ Lack of Affirmative Black Male Role Models	
➤ Lack of Support Networks	GIRLS
➤ Lack of open discussion on issues of sex/sexuality	

A majority of the youth that participated in the interviews felt that they did not know enough about HIV/AIDS and listed not having enough time as the main reason. As one female participant stated emphatically, *“Do I know enough about HIV/AIDS? Hell no! Realistically, I have not made enough time for it.* One male participant stated the following as the reason for the low HIV testing rate among youth, *“No, I never had the time to get tested. I worry about it, but don’t get tested, what’s the point of getting tested? It’s either you don’t have it or you have it, what’s the good of finding out, that’s how most people think, what good is going to happen by finding out.”* A majority of the youth did know where they could go if they wanted to get tested, that testing is free and about anonymous testing. With respect to general associations with AIDS, the

participants named “death,” “unprotected sex,” “ a lot of women, a lot of guys,” “epidemic, devastating, African, expensive,” and “population control.” With respect to the association of AIDS within the Caribbean context, these participants said they thought of “immature people,” “not taking responsibility for protecting themselves,” “AIDS is high risk in the west Indian community.” Secrecy and AIDS as a significant concern in the Caribbean community were also mentioned as important variables. One young woman commented that because “countries are so small in the West Indies, they don’t get the same attention as those countries that are in the political limelight.”

Safe Sex and HIV Testing

Safe sex seemed to be the norm and was something that they all named as what they were doing. Safe sex seemed to be understood as the expected code of conduct though they did not feel their peers were engaging in safe sex. One participant did not think anyone he knew would admit to not having safe sex. He explained he only had safe sex but further on in the interview admitted to having occasional unsafe encounters. Another participant, however, had the opposite view and suggested that many of his male friends had unsafe sex and even bragged about it. All the youth interviewed felt that unsafe sex is irresponsible, though some reported to having it occasionally or when they “*got to know the person.*” One girl said, “*Friends? I don’t have friends, I don’t have the time for friends?...I am not sure what girls are doing, if they are using condoms or not, I keep myself clean, I don’t want to be still living here until I’m 30 or 40 and from my experiences, I don’t really want to live my life in a careless way.*”

One black male participant was quite emphatic about the importance of safe sex and cited his own “misfortune” of condom breakage, which resulted in the birth of his child as a reason for this. He was very concerned about his peers whom he felt were not practicing safe sex. He reported from his experiences that “most black guys are afraid of going to doctors” and that

reputation played a significant role in their access to health care or facing up to “illness.” He also said,

My dad says black people like to look good first and everything else is second. It’s all reputation. They don’t want to go for an HIV test. They don’t want to go. They don’t know what they would do if they had AIDS, they think if I had HIV I would probably kill myself. They are scared of facing their problems. I have a friend, he said that if he found out he had HIV he would give every single girl he knows AIDS, cuz it was a girl who gave it to him, so he would give it to every girl he could for revenge.

Dysfunctional family structure and/or the lack of positive male role models were cited as the reasons for this kind of thinking. The two girls who were interviewed felt there was little discussion about this topic with their friends, either because it was considered to be private or because they generally didn’t have time for friends.

All of the youth interviewed felt that HIV is an important concern and all of them felt that they did not know enough about it or could use more knowledge on the topic. Everyone suggested the use of a positive role model from within their community, or a peer role model as extremely useful to raising awareness about this issue among youth. One woman explained, “*we need people who know about the issues, our mental health issues, our context, the context of the black community.*” Another participant stated, “*I think you must show people who are dying with HIV, or people youth can identify with, someone from their own community. I think it would scare them. Fear is a good motivator.*” It was also suggested that young black youth need more recreational venues and educational programs. One participant felt that there is a need for greater education for young girls. Girls, he felt, need to be educated from a young age about sex and power dynamics so as to avoid being taken advantage of by older men.

Having greater access to recreational and educational activities was mentioned as an important social outlet for young black men. For example, one participant argued that “*places to play ball, play sports*” would be helpful because “*if you notice most guys all hang around the subway stations and they don’t have much to do so then they start talking to girls and one thing leads to another and that’s how it all starts.*”

DISCUSSION AND SUMMARY OF FINDINGS

Service providers in Toronto and Ottawa and PHA’s from Toronto, Ottawa and Kitchener have identified several key issues pertaining to HIV/AIDS in the African and Caribbean communities. While we had the opportunity of obtaining input from 40 participants for this consultation including men, women and youth from both communities and gathered some input from the French speaking and male bisexual, gay communities, our sample size is too small for us to draw generalizable conclusions about the differences between these various sectors of the population. While we can anticipate that there are differences that need to be identified and addressed, this report has highlighted the issues, difficulties and barriers that are common to the various populations involved in this study. This consultation has focused on identifying issues affecting people who are HIV+ and/or living with AIDS. With respect to sexual attitudes and behaviours we also solicited input from Caribbean at risk youth. Their interviews highlight the importance for HIV/AIDS education, the use of role models from their own community, especially PHA’s and the barriers related to the use of HIV testing.

PHA’s and service providers recognized stigma, funding, immigration status and information, access to financial assistance, housing and treatment as priority issues affecting PHA’s. Aside from medical concerns and attending to the needs of a terminal illness, PHA’s of African and Caribbean descent find themselves in a vicious cycle of marginalization. Either due to immigration status or illness (or both), those who are HIV+ have limited opportunities for

consistent employment. This greatly affects their access to financial independence. The lack of financial means in turn has a significant impact on access to adequate housing, food, drug treatment and self-care. For immigrants with a secure immigration status, lack of Canadian work experience and non-recognition of foreign trained expertise also posed a tremendous barrier to accessing employment. PHA's were greatly concerned about family support and unification. Many felt isolated as new immigrants or outsiders to mainstream Canadian culture as well as being stigmatized by HIV/AIDS. While there was a strong need for family support and unification, few, if any were in a position to sponsor immediate family or relatives to help with their care or that of their children.

As a highly disenfranchised population, PHA's are in critical need of advocacy support on a number of issues. There is a critical need for advocacy in relation to immigration, access to HIV information and drug treatment, access to adequate and appropriate housing and access to financial assistance. There is difficulty on follow through with medical appointments largely because there are a number of issues that are affecting PHA's and the difficulty in prioritizing. PHA's felt bombarded and pulled apart by having to deal with all these issues at once without identifiable, adequate and consistent support mechanisms in place. The few support mechanisms that have proven to be successful have been greatly threatened by funding shortages and cutbacks.

A number of PHA's struggled with depression and isolation due to coping with a terminal illness and due to HIV-related stigma. They were also confronted with racism directed toward people of African and Caribbean descent in general and PHA's from endemic regions in particular. Some PHA's may also be dealing with post traumatic stress syndrome related to experiences of war, religious and political persecution. It is therefore important to recognize the link between HIV and mental health issues and services. The development of community support mechanisms and structures are extremely important for PHA's. Many emphasized the usefulness

of support groups and services where they share their HIV status and experiences. It was felt, however, that the relationship of trust between service provider and client can take many years before a client will actually access such services. Reducing HIV stigma, misinformation and ignorance are key to developing this relationship of trust. Education and consciousness raising are key to creating this kind of safe support structure. All groups of people interviewed for this consultation stressed the importance of involving people from their own communities in educational strategies and disseminations.

PHA's of African and Caribbean descent are crucial to this process of reducing stigma and increasing awareness in their respective communities, as is a proactive commitment on the part of community agencies and service providers. With respect to the former, including PHA's from African and Caribbean communities in speakers' bureau's and community speaks again emerged as an important strategy for which to educate the community and raise awareness on this issue. In order for PHA's to be in a position to be actively involved in this kind of work however, community agencies and ASO's much create systems of stability for PHA's, such as education to reduce stigma in the community, adequate housing and financial assistance. Creating a volunteer pool and hiring members from the target population were suggested as an important means for which to address the issue HIV/AIDS in African and Caribbean communities. It is important that *"issues internal to the community"* get discussed and to *"train people from endemic communities"* in order to reduce the stigma associated with it.

The service provider's focus group in Ottawa argued that providing options to communities with respect to the choice of integrated health services versus specific-HIV related services may help to alleviate some of the issues surrounding stigma and confidentiality. Having HIV related concerns integrated into general health services would help to reduce some of the conspicuousness of those seeking HIV/AIDS related support, while the specificity of HIV services would allow *"those who feel comfortable"* to seek support.

It has been observed that some PHA's do not feel comfortable with the health care system in general either due to skepticism and suspicion of western-based health care structures or because of a reliance on alternative medicines and therapies. It is important to recognize the place of alternative based therapies as well as the role of spirituality and religion in the process of healing. Working from non-western models of support and boundaries was suggested by service providers as an important way of reaching and supporting communities from endemic regions. One service provider explained how observing western models of profession-client protocol may actually hamper the process of trust and disclosure for clients, she argued that, "sharing some of the experiences from the service provider to client may be useful in the process of gaining trust."

Services for PHAs from African and Caribbean communities in Ottawa were much less developed than those in Toronto. When asked what comes to mind about services in Ottawa, the Ottawa service provider focus group said, "*Nothing. We have no HIV related services here specifically for people of African and Caribbean descent.*" Toronto, on the other hand has ethno-specific AIDS related services, such as Black CAP, ACHES and APAA as well as various ethno-specific agencies involved in HIV/AIDS related work. With respect to issues of French speaking people from endemic regions, Ottawa service providers agreed that the French speaking population was more likely to find services in French" than those who spoke other non English languages, such as Tigrinya, Swahili, etc. Interviews with French speaking PHA's in Ottawa identified racism as a key factor affecting PACD's. One participant answering the question about what issues she felt confronted PHA's of African and Caribbean descent, explained :

on this question, I think we need a big meeting in order to get solution. People of African/Caribbean are facing many problems. For example, the government ignores them because they are the minority, people of color and coming from poor countries .In my example, the government is trying to get me a house in the dangerous area, far from my doctor, how do you think I'll survive? Other people, even if they are healthy are getting housing in a nice area, clean apartment. What I want to say to the government is [they are] not suppose to ignore people who are in need."

Partnerships and holding mainstream ASO's accountable to the community emerged as recommendations from the Ottawa focus group. This is especially paramount due to the lack of funding and government cutbacks. ASO's should not just be accountable to funders, but "ethno specific agencies need to be invited to the table." Partnering was also identified as being helpful to advocating for long term funding. Separation between ethno specific AIDS organizations weakens the impact both in terms of advocacy of funding, and has a detrimental effect on PHA's who have to go to different places for different services.

The issues outlined in this report are by no means an exhaustive list of issues identified by participants. We have, however, identified a priority of concerns that emerged out of focus group and key informant interviews with PHA's and service providers. The following section outlines 10 key recommendations that emerged from the participants in this consultation process.

Recommendations

- ✓ The following 10 recommendations have emerged from those who participated in this consultation process:
- ✓ That HETF take a leading role in advocating for HIV/Aids funding for people of African and Caribbean descent both in the form of financial aid for PHA's as well as for HIV/AIDS related services so as to recover lost programs and services, maintain existing services and secure funding for further programs and services
- ✓ That HETF attempt to address the issue of fragmentation and duplication of services through considering the development of an initiative for the amalgamation of aids organizations, services and programs specifically targeting African and Caribbean communities, such as ACHES, APAA, BLACK CAP, etc
- ✓ That HETF research and identify discriminatory immigration practices toward HIV+ individuals of African and Caribbean descent and be a leading advocate for PHA's with respect to access to immigration information and HIV-specific legal services
- ✓ That HETF advocate on behalf of PHA's of African and Caribbean descent for access to safe, affordable and appropriate housing
- ✓ That HETF help to coordinate skills building workshops for PHA's of African and Caribbean descent so as to enhance access to employment opportunities
- ✓ That HETF involve PHA's in the development and implementation of HETF related activities in an advisory capacity and explore the possibility of using black cap's annual retreat as part of an ongoing annual means of connecting to and maintaining knowledge about PHA's needs, concerns and issues
- ✓ That HETF highlight the importance of stigma as a significant barrier to HIV prevention and as a critical issue affecting PHA's and therefore play a leading role in the development, coordination and dissemination of workshops and educational materials aimed at reducing HIV/AIDS stigma for people of African and Caribbean descent
- ✓ That HETF play a leading role in the development, coordination and dissemination of basic HIV/AIDS education and training as well as cultural sensitivity training for all health care professionals

- ✓ That HETF partner with relevant and interested service providers in Ottawa on significant activities and initiatives relating to HIV/aids for PACD and play a role in capacity building for service providers in Ottawa and other parts of Ontario on issues relating to HIV/AIDS for people of African and Caribbean descent

- ✓ That HETF identify and partner with other relevant research bodies, initiatives and findings such as findings in ottawa by consultants anne wright and associates, *“community consultations with client populations for the ottawa-carleton council on aids and strategic planning”*

CONSULTANTS' SUGGESTIONS

We would like to stress that the recommendations put forth in our report are recommendations that came from PHA's and those working with PHA's. In terms of gaps with respect to the Draft Strategy, we feel that the most obvious one that emerges from this phase of consultation is the absence of concerns relating specifically to PHA's. The Draft Strategy does not make any specific reference or recommendations for people living with HIV/AIDS and tends to subsume the concerns of PHA's under PACD in general terms. We do understand that the Draft Strategy, as it stands, came out of Phase One during which there was limited feedback from PHA's. It was our job, therefore, to fill this gap. While your comments on our draft report suggested that many of the issues identified were already mentioned in the Draft, such as training of health care professionals, immigration and stigma, we feel that because these issues were emphasized by PHA's as paramount, that they need to be emphasized in the Strategy. As a specific recommendation, then, as an addition to Page two of the Draft Strategy, the final strategy could delineate the issues identified by PHA's as we have outlined them in the report – namely, that PHA's stressed stigma, immigration, poverty, access to housing, inadequate training of health care professionals, racism, employment and funding as key areas of concern. Also, based on the experiences of PHA's, HETF may want to include, as part of their action plan, programs and deliverables specifically related to the support of PHA's.

On a more specific note, as a document, we found that the strategy could be made to be more reader friendly. It is very compact, generalized and dense. There is some repetition between the objectives listed under the HETF on page 1, the issues and recommendations outlined under the section “The ‘Draft’ Strategy” on Page 2 and the Principles Guiding the ‘Draft’ Strategy on Page 3 -- namely that HIV/AIDS in PACD is of paramount concern and that there is a need to promote a community based response. This again is repeated on page 5 under Goals and general Objectives of the ‘Draft’ Strategy. We suggest that these sections be reorganized and/or tightened. Also, it may be helpful if the final strategy include a written summary and explanation of short and long-term directions and suggested activities in addition to the chart outlining these activities. It would be useful

if there were a few paragraphs highlighting some of the issues and concerns emerging from the community, PHA's and service providers so that readers who may be unaware or unfamiliar with HIV/AIDS can have a context for the list of short and long term goals and suggested activities.

Appendix 1: EXECUTIVE SUMMARY

THE HIV/AIDS EPIDEMIC AMONG PERSONS FROM HIV-ENDEMIC COUNTRIES IN ONTARIO, UPDATE TO 2000: SITUATION REPORT

EXECUTIVE SUMMARY

**THE HIV/AIDS EPIDEMIC AMONG PERSONS FROM
HIV-ENDEMIC COUNTRIES IN ONTARIO, UPDATE TO 2000:
SITUATION REPORT**

Robert S. Remis, Elaine P. Whittingham, Department of Public Health Sciences, University of Toronto

In our original report of November 1999, we presented analyses of available data and the results of statistical modeling to characterize the HIV epidemic among persons living in Ontario who were born in countries in the Caribbean or sub-Saharan Africa (AHIV-endemic regions) historically and as of December 1998. For the present update, we extended the analyses to December 2000. This was carried out by using newly available data on immigration to 1999 and estimated HIV prevalence among immigrants and factoring in the estimated number of Aindigenous@ HIV transmissions and HIV-related deaths since December 1998.

In general, since HIV data does not reliably capture data on birth or residence in an HIV-endemic country, it is difficult to draw precise conclusions about patterns of HIV diagnoses in this population or whether persons from HIV-endemic regions tend not to go for testing. The analysis of reported AIDS cases indicated that persons from HIV-endemic regions accounted for an increasing proportion of cases in Ontario, especially since 1996; this group represented 17% of AIDS cases in 1999. Most cases were less than 45 years old at time of diagnosis. Further, an increasing number of AIDS cases in later years were among persons born in sub-Saharan Africa. The majority of deaths due to AIDS in this population occurred after 1990 and mainly among persons under 50 years old, although women tended to die at an earlier age than men. The majority of HIV-positive women in a database of HIV-infected mothers and their infants were born in the Caribbean or sub-Saharan Africa; further, over half the confirmed HIV-positive infants in the database were born to women from these regions.

Our updated model indicates that, as of December 2000, approximately 2,800 persons from HIV-endemic regions and residing in Ontario were living with HIV infection (1,800 from the Caribbean and 1,000 from sub-Saharan Africa). The HIV epidemic among this population dates primarily since 1990 for most countries modeled, with the exception of Jamaica where the epidemic appears to have been present earlier. More HIV-infected persons were born in the Caribbean, though prevalence rates were higher for the sub-Saharan African countries. The annual rate of increase of HIV infections approximated 10%, representing about 240 more HIV infections each year in the past few years. Though modeled figures were obtained using methodologies which have important limitations, the estimations represented a good fit with available reported data and were consistent with 1996 projections for HIV prevalence among this population. For these reasons, we are confident our results are a plausible indication of the extent of HIV infection among this population.

Persons who immigrate to Ontario from an HIV-endemic region represent an important part of the Ontario epidemic, preceded only by men who have sex with men (MSM) and injection drug users (IDUs). Whereas overall HIV prevalence rates among immigrants from these regions may not appear substantial, rates are about 50-fold higher than among other heterosexual non-injecting persons in Ontario. Furthermore, modeling techniques which estimated the number of HIV infections acquired in Canada revealed that considerable transmission may be occurring after residence is established here, suggesting that a substantial proportion (30-45%) of HIV infections are not Aimported@.

A non-negligible proportion of HIV-infected men emigrating from HIV-endemic regions reported having had sex with men. Though not the primary focus of the present study, we estimate there may be 400 or

more HIV-infected MSM from HIV-endemic countries and several thousand men at risk for infection. These persons represent an important segment of the immigrant population who until now have not been the focus of specific research or preventive interventions. MSM from HIV-endemic countries explains in part the high male: female ratio observed in our analyses (6:1 among persons from the Caribbean and 3:1 among those from Africa).

The results of this report highlight the need for epidemiologic research to validate results obtained through statistical modeling, specifically with regard to the substantial rate of HIV transmission in Canada. Social and behavioural studies are also needed to better understand the determinants of transmissions among immigrants from HIV-endemic regions. Political will at the community, provincial and national level is required to support further investigations of this public health problem and develop effective preventive interventions.

Appendix 2: Interview Questionnaires

**HETF Consultant Team
Moderator's Guide**

Draft Questionnaire

PLWA's, Individual Interviews

1. What is your age?
2. Country of Origin?
3. Ethnicity?
4. How many years have you been living in Canada?
5. What is your immigration status?
6. Gender?
7. What languages do you speak/write/read?
8. Can you describe your living arrangements?
9. Are you employed? If so, what is your job?
10. Are you receiving any social assistance/welfare?
11. Do you have a health care plan? Are you receiving any benefits?
12. What issues/difficulties do you feel people of African/Caribbean descent who are HIV+ face?
13. How long ago were you diagnosed as being HIV+?
14. How did you find out you were HIV+?
15. How do you think you contracted the illness?
16. Do you remember your initial reaction?
17. What did you/have you done to cope?
18. Where did you get the information you needed in relation to HIV/AIDS?
19. Who have you been able to talk to for support? Any family or community? How was their reaction? Was this the sort of reaction you expected?
20. How has being HIV+ affected your relationships within the family? Within the community?
21. Do you feel that your positive status has affected your personal life?
22. Do you have a partner? Is your partner supportive? How? If not, why not?
23. What supports has your partner/family members used and have they been helpful?

24. Do you have a family doctor?
25. What is the country of origin of your family doctor?
26. Do you feel comfortable with your family doctor?/Can you think of anything that would make you feel more comfortable?
27. Have you used any AIDS related services? If so, which ones?
28. Are you satisfied with these services?
29. Are there any services/supports that you feel are missing?
- 30.
31. Are you taking medication?
32. How do you afford treatment?
33. Have you participated in any clinical trials? If so, why? And how was the experience?
34. What do you think needs to be done within the community to address the issue of HIV/AIDS?
35. Would you be interested in participating in any kind of community advisory committee/board/working group on HIV/AIDS?
36. Are there any other issues do you feel are important to you?

**HETF Consultant Team
Moderator's Guide
Draft Questionnaire**

Service Providers

1. What is the name of your agency, which area of the city is your organization located and what services does your agency provide?
2. How long have you been working with your organization?
3. What is the profile of your clients – age, gender, ethnicity, SES, etc., What percentage of your clients are African and/or Caribbean
4. Does your organization have any services/programs that relate specifically to HIV/AIDS?
5. How do your clients usually find out about your services?

6. What do you think some of the issues are relating to HIV/AIDS in African/Caribbean communities?
7. What kinds of issues do you feel that your clients are facing in relation to HIV/AIDS?
8. Do these issues differ depending on ethnicity, gender or other variables?
9. Do you feel that you are able to adequately address the needs of your clients?
10. What are some of the issues that come up for you as a service provider?
11. What are some of the major barriers you experience when attempting to deliver services to this population?
12. Are there any programs your organization has put in place to overcome these barriers?

13. What kind of referrals does your agency make?
14. What sorts of services/programs do you feel are missing?
15. If relevant, has your agency undergone any formal cultural sensitivity training?
16. Do you think you know enough about the issues relating to HIV/AIDS in African/Caribbean communities?
17. What kind of strategic plan do you think needs to be put in place to address HIV/AIDS in PACD communities?
18. Would be you interested in being part of an ongoing community advisory committee/board/taskforce/working group related to HIV/AIDS?
19. Has the Draft address most of the significant issues that affect PACD with respect to HIV/AIDS?
20. Are there any issues that you think should be prioritized?
21. Are there any issues that are missing, in your opinion?
22. Is there any further input regarding short and mid term suggested activities?

**HETF Consultant Team
Moderator's Guide**

Draft Questionnaire

Youth, Individual Interviews

37. What is your age?
38. Country of Origin?
39. How many years have you been living in Canada?
40. Gender?
41. Can you describe your living arrangements?
42. How is it that you came to reside at Eva's Phoenix?
43. How long have you been at Eva's Phoenix?
44. Are you employed? If so what is your job?
45. What is the first thing that comes to mind when you hear the words HIV/AIDS?
46. What is the first thing that comes to mind when you hear the words HIV/AIDS in the African or Caribbean communities?
47. What issues/difficulties do you feel people of African/Caribbean descent who are HIV+ face?
48. How do you feel people's attitudes toward this issue may be back home? How about here?
49. Do you think people you know in the Caribbean community are practicing safe sex?
50. Do you think people you know go for HIV testing? If not, why?
51. If you found out that you were HIV+, how do you think you would feel?
52. If you found out that you were HIV+, where would you go for help?
53. If you found out that you were HIV+, how do you think your community would react?
54. What kinds of suggestions do you have to raise awareness among Caribbean youth on issues related to HIV/AIDS?
55. Among your top ten list of priorities is HIV/AIDS one of them?
56. What are some of your priorities, concerns?

Appendix 3: List of Service Providers

LIST OF SERVICE PROVIDERS

INDIVIDUAL INTERVIEWS

Sunnybrook Hospital
HIV/AIDS Clinic
2075 Bayview Ave.
Toronto, ON
M4N 3M5
(416)480-6044

Julie (Nurse) & Linda (Researcher)

Mount Sinai Hospital
600 University Ave.
Toronto, On
M5G 1X5
(416)586-8694

Judith Schenkman (Social Worker & Psychotherapist)

Ethiopian Association of Toronto
2064 Danforth Ave.
Toronto, ON
M4C 1J6
(416)694-1522

Yeshoalul Meskel (Crisis Counselor)

Black CAP
110 Spadina Ave., Suite 207
Toronto, ON
M5V 2K4
(416)977-9955

Lena Soje (Support Worker)

Nellie's
970 Queen St. E
Box 98118
Toronto, ON
M4M 1J0
(416)461-1084

Asha Harris

OAN
44 Victoria St. Ste. 915
Toronto, ON
M5C 1Y2
(416)364-4555

Jose Franco (Board Member)

FOCUS GROUP DISCUSSIONS

In Toronto:

Toronto PEOPLE WITH AIDS Foundation
399 Church St. 2nd fl.
Toronto, ON
M5B 2J6
(416)506-1400

Bernadette Dondo & Paul Landers

Hassle Free Clinic
556 Church St. 2nd fl.
Toronto, ON
M4Y 2E3
(416)922-0566

Edith

In Ottawa:

AIDS Committee of Ottawa
Living
207 Queen St. 4th fl.
Ottawa, ON
K1P 6E5
(613)238-5014

Nadine Riopelle (Program Coordinator, The Room)

Ottawa Rape Crisis Centre
(Address not available)
(613)562-2334

Josephine Basudde (Counselor)

Ste. Anne Medical Centre/Source
500 Old Patrick St
Ottawa, ON
K1N 9G4
(613)789-1552

Ana Maria Calderon (Social Worker)

OASIS, Sandy Hill Community Centre
Hannah
250 Somerset Est.
Ottawa, ON
K1N 6V6

Roger Harvey (Student of Addiction) &
Cowen (RN, Acting Co-Manager)

City of Ottawa, Sexual Health Centre
Health)
179 Clarence Ave.
Ottawa, ON
1-800-267-7432

Zhaida Uddin (Project Officer: Multicultural

The Ottawa Hospital – Module G –
General Campus
501 Smyth Rd
Ottawa, ON
K1H 8L6

Rina Arseneault (Social Worker)