Strategy to Address
Issues Related to HIV Faced by People in Ontario
From Countries Where HIV is Endemic

Prepared by the

The HIV Endemic Task Force

December 2003

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Glossary of Acronyms

ACCHO	African and Caribbean Council on HIV/AIDS in Ontario
ACHS	African Community Health Services
AHRO	Association of HIV/AIDS Researchers of Ontario
APPA	Africans in Partnership Against AIDS
ASAP	As Soon As Possible
ASO	AIDS Service Organization
BCAP	Black Coalition for AIDS Prevention
CAHR	Canadian Association of HIV Research
CAS	Canadian AIDS Society
CHC	Community Health Centre
CMSC	Centre médico-social communautaire
HETF	HIV Endemic Task Force
IDU	Injection Drug User
LCDC	Laboratory Centre for Disease Control (now titled Centre for Infectious Disease Prevention & Control), Health Canada
HC	Health Canada
HPPB	Health Promotion and Protection Branch (now titled Population & Public Health Branch), Health Canada
MP	Member of Parliament (Federal)
MPP	Member of Provincial Parliament
MSM	Men Who Have Sex With Men (defined as gay or bisexual men, or men who have sex with men who do not self-identify as being gay or bisexual).
NGO	Non-Governmental Organization
OACHA	Ontario Advisory Council on HIV/AIDS
OAN	Ontario AIDS Network
OHIP	Ontario Health Insurance Plan
OHTN	Ontario HIV Treatment Network
PLWHA	Person Living With HIV/AIDS
PPHB	Population & Public Health Branch, Health Canada
SSHRC	Social Sciences & Humanities Research Council
STI	Sexually Transmitted Infection
TORs	Terms of Reference
UNAIDS	Joint United Nations Programme on HIV/AIDS
WHIWH	Women's Health In Women's Hands Community Health Centre
YCS	Youth Clinical Services Inc

Introduction

In an effort to promote a timely, coordinated and adequate response to issues related to HIV faced by people in Ontario from countries where HIV is endemic (i.e. African and Caribbean communities), the HIV Endemic Task Force (HETF) developed this Strategy. It is important to note that the Strategy is intended to be a framework or "roadmap" to coordinate and guide action. It does not provide program or project detail, or workplans. Specific objectives, activities and outcome indicators will be developed as agencies and/or coalitions of agencies begin to implement and further refine the Strategy's 'suggested directions'. In addition the Strategy will be reviewed and revised (as needed) every two to five years.

Terminology

For some people the term HIV-endemic is problematic. It is in fact an epidemiologic term that refers to countries or populations where there is a high prevalence of HIV infection in the general population (i.e. generally greater than 1%), and the predominant mode of transmission is heterosexual contact. Currently, most countries in the Caribbean and Sub-Saharan Africa have been classified as HIV-endemic. The Joint United Nations Programme on HIV/AIDS (UNAIDS) refers to HIV-endemic as a 'generalized epidemic' as opposed to an epidemic within distinct groups of the population.

This Strategy strives to address issues related to HIV faced by people in Ontario from countries where HIV is endemic. Consequently, given the current composition of Ontario's population and the present state of the HIV epidemic in Ontario, the Strategy is primarily geared to people of African and Caribbean descent. Thus the document refers to "African and Caribbean people and communities" rather than HIV-endemic communities.

The HIV Endemic Task Force (HETF)

History

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

In 1998, a number of agencies formed a working group. The organizations involved at the time included: African Community Health Services (ACHS), Africans in Partnership Against AIDS (APAA), Black Coalition for AIDS Prevention (BCAP), Laboratory Centre for Disease Control (now titled the Centre for Infectious Diseases Prevention & Control) of Health Canada and the AIDS Bureau, Ontario Ministry of Health and Long Term Care.

The working group decided that it needed a clear picture of the status of the HIV/AIDS epidemic among people from the African and Caribbean communities. In late 1998, the group asked Dr. Robert Remis to prepare an epidemiologic situation report to better understand the issue of HIV infection among people from countries where HIV is endemic. The study examined available data for the period 1981 to 1998 from databases in Ontario to better characterize and quantify HIV incidence and prevalence in these populations. The Remis report, entitled *The HIV/AIDS Epidemic Among Persons From HIV-Endemic Countries in Ontario, 1981-98: A Situation Report*, was released in November 1999. An updated Executive Summary of the report is attached as Appendix 1.

The Remis report verified the trends front-line service workers were seeing and established the need for a Strategy to address the issue. The working group invited other organizations and individuals working with African and Caribbean communities to begin drafting a Strategy. Rexdale Community Health Centre, Centre médico-social communautaire (CMSC), Youth Clinical Services Inc., Women's Health In Women's Hands (WHIWH), Health Promotion and Protection Branch (Ontario Region) [1]of Health Canada (replaced LCDC on the working group), and Toronto Public Health joined and the working group was re-named the HIV Endemic Task Force (HETF).

Goals and Work of the HETF

The HETF identified the following goal for itself*: "to reduce the incidence of HIV among people in Ontario from countries where HIV is endemic (i.e. African and Caribbean communities) and to improve the quality of life for those infected and affected by HIV/AIDS."* The general objectives of the HETF were:

1. to coordinate the work of agencies, institutions and policy makers working with and for African and Caribbean people regarding prevention, education, health promotion, care and support;
2. to facilitate community development in response to HIV/AIDS challenges; and,
3. to identify research needs, priorities and opportunities.

The HETF identified the need for urgent action by government departments, health care agencies, HIV/AIDS service organizations, settlement agencies, social service agencies and the communities themselves. In addition to developing this Strategy, the Task Force engaged in ongoing education and advocacy work on the issue and built links with existing HIV/AIDS strategies, including the Ontario Provincial HIV/AIDS strategy and the federal Canadian Strategy on HIV/AIDS, to ensure both provincial and national attention and action on this urgent issue.

[1] Now titled Population & Public Health Branch (Ontario Region), Health Canada

The Process Guiding the Development of the Strategy

The Strategy was developed collectively by the founding members of the HETF. See Appendix 2 for a list of HETF member agencies.

Two Phases of consultation informed the final version of the Strategy.

Phase One

The Phase One consultation involved telephone interviews with selected service providers, researchers, advocates and non-governmental organizations (NGOs) working with African and Caribbean people.

The data generated by the telephone interviews contained a number of common themes, issues and recommendations including the need for:

- immediate attention and dedication of resources to the increasing rates of HIV infection among African and Caribbean people;
- ongoing consultation with African and Caribbean communities, and service providers working with these communities geared to building a community-based response that recognizes the diversity within and between communities of people from countries where HIV is endemic;
- approaches that address the broader social context that affects the health of individuals and communities (i.e. culture, gender, socio-economic status, social support networks, social environments);
- an integrated health care approach to the delivery of HIV prevention, care, treatment and support;
- culturally competent programs and services that are accessible and relevant to all African and Caribbean people and communities; and
- policies rooted in the day-to-day reality of service and program delivery.

Data from the telephone interviews also indicated a number of key directions and suggested activities including:

- advocating for additional funding for linguistic and cultural interpretation, translation of resource materials and coverage for the costs of medications;
- identifying, supporting and promoting culturally appropriate & accessible HIV prevention, care, treatment & support programs and services;
- developing/piloting alternative modes of service/program delivery (e.g. off-site/mobile service delivery; assistance with basic needs such as housing, food, medical care, immigration; and peer support that is culturally competent);
- supporting community education and mobilization initiatives within African and Caribbean communities, and working with the informal support networks that exist in these communities;

- breaking the silence and creating a supportive environment for prevention work; and
- promoting a broad base of relevant research (e.g. psycho-social research, epidemiology & surveillance, research with a service delivery component, best practices research, needs assessments).

The expertise and experience of HETF members and the data generated by these telephone interviews was used to develop a Draft Strategy. Next, the draft Strategy and a questionnaire were mailed out to a wide range of African and Caribbean community members and service providers, and the broader health and social service sector working with African and Caribbean communities. And, in November 2001, the *"For Us, By Us, About Us"* Community Forum was held in Toronto.

Key input from the mail out survey and the Community Forum included the need for the Strategy to:

- address the limited funding from government;
- increase African / Caribbean representation in service provision;
- facilitate discussion of differences among African people;
- integrate HIV/AIDS education and awareness in the school curriculum, particularly in Catholic schools;
- promote opportunities for communities to talk about homosexuality, and hear and learn about the impact of negative attitudes about homosexuality;
- recognize that fear of disclosure has resulted in separation of families and violence toward women, displacement of families, poverty, orphans/children in foster care; and
- develop alternate ways to reach people and communities (e.g. sports venues, popular theatre, music, media, faith groups & religious leaders, take community forums into the communities, focus groups, etc,,.)

Participants also encouraged the HETF to:

- ⇒ broaden the membership of the HETF as soon as possible to include members from other parts of the province especially Ottawa, and to include representation from all the affected African and Caribbean communities;
- ⇒ recognize that community forums are an important stimulus for debate and continued discussion and should occur on a regular basis; and
- ⇒ work with funders to ensure effective monitoring of funds (i.e. that funding given to organizations actually supports effective programming).

Phase Two

Building on the input gained in Phase One, the Phase Two consultation conducted targeted focus groups with African and Caribbean people living with/affected by HIV/AIDS, and with service providers in Toronto and Ottawa working with African and Caribbean communities.

Findings highlighted stigma, racism, employment issues, immigration, funding, training of health care professionals, and access to housing, financial assistance and treatment as key issues affecting African and Caribbean people living with/affected by HIV/AIDS.

Findings of the Phase Two consultation included recommendations that the HETF:

- ⇒ play a leading advocacy role with respect to African and Caribbean people living with/affected by HIV/AIDS regarding access to immigration, housing, financial assistance and consistent employment;
- ⇒ be involved in the development and dissemination of educational strategies aimed at alleviating different forms of stigma faced by African and Caribbean people living with/affected by HIV/AIDS;
- ⇒ consider the amalgamation of ethno-specific HIV/AIDS related services and programs; and
- ⇒ shift the focus from funding of needs assessments to an emphasis on program development and service delivery for African and Caribbean people living with/affected by HIV/AIDS.

The themes, issues and recommendations from all of the consultations have become an integral part of the Strategy and the development of the African and Caribbean Council on HIV/AIDS.

Consultation Reports

Detailed reports of the *"For Us, By Us, About Us"* Community Forum and the Phase Two Community Consultations are available from:

Canadian HIV/AIDS Information Centre
Centre canadien d'information sur le VIH/sida
400 - 1565 avenue Carling Avenue
Ottawa, ON K1Z 8R1

Toll Free: 877-999-7740 Phone: 613-725-3434 Fax: 613-725-1205

Email: aidssida@cpha.ca Web site: www.aidssida.cpha.ca

On the Internet at:

www.phs.utoronto.ca/ - see "Links", or at
www.hiv-cbr.net

Principles Guiding the Strategy

The Strategy begins from the assumption that while African and Caribbean people and communities share many commonalities, they are not homogeneous. African and Caribbean people and communities have multiple identities rooted in religion, culture, sexuality, class, ethnicity, gender, migratory status[2], etc.. These identities shape the context of people's lives and their communities. In turn, this context affects people and communities' self-identity and self-esteem, their living and working conditions, their safety, their health, their behaviours and their options or 'choices'. An understanding of these contexts and multiple identities is key. Equally important is the recognition that African and Caribbean people and communities live within complex and intersecting power structures largely determined by 'mainstream' society (i.e. what Himani Bannerji [3] refers to as "the social relations of ruling coded as gender, class and race").

The following key principles are inherent in the Strategy's goal, objectives, directions and suggested activities. The Strategy:

- asserts that the increasing rates of HIV infection among African and Caribbean people is an urgent issue that requires immediate attention and dedication of resources to prevention of HIV transmission and to the care, treatment and support of those living with and affected by HIV/AIDS;
- recognizes that efforts to address the issue of HIV among African and Caribbean people requires consultation and collaboration with African and Caribbean communities and groups and service providers working with and within these communities;
- is geared to building and promoting a community-based response that recognizes the diversity within and between African and Caribbean communities across Ontario;
- recognizes that in order to be most effective, HIV programming needs to work in a broad social context that addresses the determinants of health. These determinants of health influence the health of individuals and communities and include such things as culture, gender, socio-economic status, social support networks, and social environments;
- emphasizes the need for gender-based analyses and programming given the reality that gender inequality and gender-based hatred and violence affect all women's lives, and the fact that African and Caribbean women must deal with all the barriers and issues that African and Caribbean people face plus the additional isolation and marginalization of being women within these communities, and, the physiological differences between men and women that

[2] i.e. refugee, immigrant, Canadian-born, etc.

[3] "Returning the Gaze: An Introduction" in Bannerji, Himani (ed.) *Returning the Gaze: Essays on Racism, Feminism, and Politics.* Toronto: Sister Vision Press. 1993. Pg. xxvi.

render women more biologically vulnerable to HIV infection through heterosexual sex than are men [4];

- recognizes that racism and other types of discrimination influence African and Caribbean people's response to HIV/AIDS. Racial discrimination limits not only access to employment and housing, but access to HIV/AIDS information and services developed to reduce transmission, provide treatment, care and support of those infected and affected by HIV/AIDS within African and Caribbean communities. All initiatives targeted to African and Caribbean people must recognize and deal strategically with this factor;
- stresses the need to address stigma - both the stigma and racism promoted by 'mainstream' society against African and Caribbean people and communities; and the stigma and denial promoted within African and Caribbean communities which marginalizes African and Caribbean people living with HIV/AIDS and their families/caregivers thereby endangering their physical and mental health, and significantly reducing the effectiveness of HIV/AIDS prevention, care, treatment and support initiatives;
- promotes the delivery of HIV prevention, care, treatment and support strategies, programs and services within an integrated comprehensive health care approach (i.e. a broad range of health care services not only HIV specific services);
- acknowledges that HIV prevention, care, treatment and support strategies and initiatives occur within a continuum of program and service delivery;
- requires that programs and services involve African and Caribbean people; be culturally competent; and be accessible and relevant to all African and Caribbean people including children & youth, women, gays/lesbians/bisexuals/transgendered/ heterosexuals, men who have sex with men[5] (MSM), and injection drug users (IDUs);
- identifies the need for mechanisms to link the macro and the micro levels (i.e. policy and programs/services), and acknowledges that policies must be rooted in the day-to-day reality of service and program delivery (i.e. policies should be informed by, and supportive of service and program initiatives);
- makes every effort to increase coordination and reduce duplication, and be integrated into other provincial and federal HIV/AIDS strategies and polices; and

[4] "*The per-contact risk of sexual transmission from an HIV-infected man to an uninfected woman is greater than that in the opposite direction. Though there is continued controversy about the degree of this difference, most experts feel it is in the range of two to four times."* Verbal communication with Dr. Robert Remis, Department of Public Health Sciences, University of Toronto, Canada, October 2003.

World Health Statistics Quarterly / Rapport Trimestriel De Statistiques Sanitaires Mondiales 49(1996). Page 106.; Canadian AIDS Society. 1997/98 National AIDS Awareness Campaign: The Changing Face of AIDS. Ottawa: Canadian AIDS Society. 1997. Module 2-4.

[5] MSM is defined as gay or bisexual men, or men who have sex with men who do not self-identify as being gay or bisexual.

- identifies the potential for the African and Caribbean Council on HIV/AIDS in Ontario (ACCHO) to play a key role in coordinating a response among government departments, HIV/AIDS service organizations, public health departments, health care and social service agencies, and the different levels of government.

These principles guided the development of the Strategy, and they will be a central component of its implementation.

Goal and General Objectives of the Strategy

Goal:

to reduce the incidence of HIV among African and Caribbean people in Ontario and to improve the quality of life for those infected and affected by HIV/AIDS.

General Objectives:

1. To coordinate the work of agencies, institutions and policy makers working with and for African and Caribbean people regarding prevention, education, health promotion, care and support.
2. To facilitate community development in response to HIV/AIDS challenges.
3. To identify research needs, priorities and opportunities.

The next section outlines some key Directions and Suggested Activities that will contribute to achieving the goal and objectives of the Strategy. Some of the Directions and Suggested Activities are relevant to more than one of the General Objectives, however for the purposes of clarity and brevity they appear under the General Objective that they are most directed toward.

In effort to promote realistic planning the Suggested Activities have been defined as short-term or mid-term. Suggested Activities have been allocated to the time frame in which they are likely to begin, it is recognized that some of them are ongoing and/or may span more than one category.

The Strategy is intended to be a framework or “roadmap” to coordinate and guide action. It does not provide program or project detail, or workplans. Specific objectives and activities and outcome indicators will be developed as agencies and/or coalitions of agencies begin to implement and further refine the Strategy’s ‘suggested directions’. In addition the Strategy will be reviewed and revised (as needed) every two to five years.

Directions and Suggested Activities

Objective 1: to coordinate the work of agencies, institutions and policy makers working with and for African and Caribbean people regarding prevention, education, health promotion, care and support.

DIRECTIONS	SUGGESTED ACTIVITIES	
	Short-Term	**Mid-Term**
Advocate for a commitment to and resources to implement a province-wide strategy to reduce HIV infection among African and Caribbean people that includes prevention; care, treatment & support; research; and advocacy/community mobilization.	Link into existing initiatives & organizations wherever possible and put African and Caribbean people and communities on the agenda – e.g. OACHA, OAN, CAS, Ministerial Council on HIV/AIDS, National Women's Reference Group on HIV/AIDS. Involve African and Caribbean people in the strategy ASAP, including well-respected community & religious leaders, and organizations of African and Caribbean people. Link with, and learn from the existing advocacy/lobby expertise and the connections within the HIV/AIDS movement.	Promote recognition of African and Caribbean people and communities' issues/needs within federal public health policies and health promotion strategies. Ensure that provincial and local public health units develop policies and programs on HIV prevention, care, treatment and support that are geared to, and appropriate to African and Caribbean people and communities. Recruit a high profile champion of African or Caribbean descent (e.g. Maestro). Conduct and promote direct advocacy (i.e. writing to MPs and MPPs re issues of concern) Develop a 'how to advocate' guide by adapting and updating existing ones.

DIRECTIONS	SUGGESTED ACTIVITIES	
	Short-Term	**Mid-Term**
Break the silence and create a supportive environment for prevention work. *(It is important to note that all of the following organizations need to be involved in prevention work: settlement services; health services; youth agencies; schools; community organizations for endemic communities; language training and job training programs; clinics; physicians' practices; community health centres; mosques; churches; expatriate national services (country specific); HIV/AIDS organizations; AIDS Bureau; funders, universities and student associations.)*	Develop prevention objectives for African and Caribbean people and communities that are targeted at men & women; youth and school programs; condom use; pregnant women; people using/abusing substances; and disclosure & partner notification. Include secondary prevention issues (i.e. work with HIV + people re prevention of transmission, vertical transmission) in all prevention strategies.	Use the inventory of points of access to service (described in the next section) to target prevention initiatives where significant numbers of African and Caribbean women and men access services. Building from existing work, draft HIV testing, prevention, disclosure & partner notification guidelines for African and Caribbean men and women. Promote & support culturally appropriate and gender sensitive healthy sexuality programs, and STI prevention, care and treatment programs with active HIV prevention components, and culturally appropriate and gender sensitive prevention programs in schools. Research, assess and adapt to African and Caribbean people and communities (as needed) initiatives to counter stigmatization within communities, particularly for MSM[6]. Utilize municipal, provincial and federal healthy babies/healthy children programs to develop and implement

[6] MSM is defined as gay or bisexual men, or men who have sex with men who do not self-identify as being gay or bisexual.

DIRECTIONS	SUGGESTED ACTIVITIES	
	Short-Term	**Mid-Term**
		prevention strategies.
Hold organizations accountable for providing services to African and Caribbean people and communities.	Draft a statement of principles & list of key actions that organizations can adopt and commit to implementing.	Promote "creating supportive environments" – e.g. encourage agencies to recognize, plan for and resource the advocacy work that front-line workers must do on behalf of African and Caribbean people and communities.
Provide an accountability and coordinating mechanism for work with African and Caribbean people and communities in Ontario through the African and Caribbean Council on HIV/AIDS in Ontario (ACCHO).	ACCHO members to work with existing policy forums re having them integrate issues related to African and Caribbean people and communities into their mandates/strategies – i.e. existing provincial and national HIV/AIDS strategies, Ministerial Council on HIV/AIDS, OAN, CAS, National Women's Reference Group on HIV/AIDS, OACHA, Canadian Institutes of Health Research, SSHRC, OHTN. ACCHO to include more agencies working with African and Caribbean people and communities (e.g. CHCs, settlement agencies, hospital clinics, etc.) and be more provincially representative.	Organize a roundtable meeting with key stakeholders (HIV & non-HIV) to launch/promote the Strategy - could be a working meeting and the ACCHO could have some concrete suggestions re 'this is what you can do to help out'. Develop an open, transparent and accountable process that involves African and Caribbean people and communities and organizations (including non-HIV specific ones) working with African and Caribbean people and communities for establishing priorities in research, prevention initiatives, and, care, treatment & support initiatives.

DIRECTIONS	SUGGESTED ACTIVITIES	
	Short-Term	**Mid-Term**
Provide an accountability and coordinating mechanism for work with African and Caribbean people and communities in Ontario through the ACCHO - continued.	Write letters to policy forums and national bodies re issues of importance to HIV/AIDS among African and Caribbean people and communities (e.g. letter to Health Canada opposing mandatory testing of immigrants). ACCHO to assess the need for a staff-person to coordinate the ACCHO, and if needed to identify resources for the position.	Once the priorities have been established approach agencies and organizations with specific/concrete requests – e.g. public health – we need a brochure on HIV prevention for African women; OHTN we need you to issue a targeted call for research on the following, etc.. ACCHO will function as a co-ordinating & overseeing group to monitor the implementation of the Strategy & and as a mechanism to assess and re-direct programs as needed.

Objective 2: to facilitate community development in response to HIV/AIDS challenges faced by African and Caribbean people and communities.

DIRECTIONS	SUGGESTED ACTIVITIES	
	Short-Term	**Mid-Term**
Identify and promote culturally appropriate, gender-sensitive & accessible HIV prevention, care, treatment & support programs and services delivered within a framework of comprehensive health and social services.	Do an inventory of where African and Caribbean women and men are accessing health and social programs and services to identify points of access for HIV prevention, care, treatment & support initiatives. (e.g. where African and Caribbean women and men gather, ESL classes, settlement agencies, etc.) Establish anonymous HIV testing sites where African and Caribbean women and men are currently accessing services. Develop an up to date, reliable, comprehensive resource of what programs/services exist; the resource would also highlight services of particular relevance to African and Caribbean women and men (e.g. CHCs offer health care to people without OHIP cards, identify programs/services that are relevant and accessible to African and Caribbean women, BCAP has Caribbean/African service providers, CMSC offers services in French, etc.)	Identify, document and promote culturally sensitive/competent and gender sensitive 'best practices'. Identify current gaps in culturally sensitive/competent and gender sensitive 'best practices' and research ways to fill the gaps. Advocate for additional funding for the unique services needed by African and Caribbean women and men such as linguistic & cultural interpretation, translation of resource materials, accompaniment to health & social service appointments, coverage for costs of medications, health care for 'undocumented' people, etc.

DIRECTIONS	SUGGESTED ACTIVITIES	
	Short-Term	**Mid-Term**
Identify and promote culturally appropriate & accessible HIV prevention, care, treatment & support programs and services delivered within a framework of comprehensive health and social services - continued.	Establish a mechanism to distribute the resource (detailed above) and keep it up to date.	Develop/pilot alternative modes of service/program delivery (e.g. off-site/mobile service delivery; alternative therapies such as art therapy, story telling, relaxation that are culturally appropriate; assistance with basic needs – housing, food, medical care, immigration; and peer support that is culturally competent and gender sensitive). Look to other sectors (e.g. cancer care models may be useful re children living with/affected by HIV).
Support capacity building initiatives within African and Caribbean communities and existing African and Caribbean organizations to respond to HIV/AIDS.	Support community education and mobilization initiatives within African and Caribbean communities. Identify and work with informal support networks that exist within African and Caribbean communities.	Link larger more established agencies with smaller and/or newer organizations to provide infrastructure and/or mentoring.

DIRECTIONS	SUGGESTED ACTIVITIES	
	Short-Term	**Mid-Term**
Educate/train health care providers in cultural competency/cultural sensitivity and gender equity/gender-based analysis.	Provide forums to share & learn for service providers.	Establish standards and guidelines for cultural competency and gender equity/gender-based analysis training of health care providers. Provide training & resources re how to advocate for immigrants & refugees regarding immigration and settlement issues.

Objective 3: to identify research needs, priorities and opportunities.

DIRECTIONS	SUGGESTED ACTIVITIES	
	Short-Term	**Mid-Term**
To establish research priorities that promote a broad base of relevant research.	Contact existing funding bodies (e.g. OHTN) and request that they promote research in priority areas identified by the ACCHO through 'challenge grants', directed calls for proposals, etc. Approach researchers known to be interested in this area and ask them to work with the ACCHO to research particular issues. Establish a Working Group of ACCHO members, researchers, organizations working with African and Caribbean people and communities, and research funding bodies to establish research priorities and support research in areas of critical importance to addressing HIV among African and Caribbean people and communities.	The Working Group will strive to promote a range of research including: - epidemiologic (e.g. #s infected, # partners, etc.); - prevention (e.g. effective program models); - psycho-social (e.g. people's norms, practices, behaviours, etc.); - gender-based analysis; - participatory & action research; - research with a service delivery component; - formal program evaluation; - best practices research (e.g. effective service models for African and Caribbean communities); - needs assessments; - program inventories; - policy impact studies (e.g. impact of immigration & refugee policy re access to health care); - priority populations (e.g. African and Caribbean MSM)[7];

[7] MSM is defined as gay or bisexual men, or men who have sex with men who do not self-identify as being gay or bisexual.

DIRECTIONS	SUGGESTED ACTIVITIES	
	Short-Term	**Mid-Term**
To establish research priorities that promote a broad base of relevant research - continued.		- unpacking and understanding 'stigma'; etc. Assess key government policies regarding their potential negative impact on HIV prevention, care, treatment & support among African and Caribbean people and communities (e.g. immigration policies), and suggest how they need to be changed. Promote research into the use and effectiveness of ethno-specific medicines and therapies.
To reduce the potential negative impacts of research on African and Caribbean people and communities.	Co-ordinate research initiatives so communities are not overwhelmed by research requests. Ensure researchers are aware of and are building on existing migration and integration research, and that they have contacted sites of current research, such as the Metropolis Centres of Excellence on Immigration and Integration, re studies in progress. Support capacity building for community based research within African and Caribbean communities (e.g. research partnerships, mentoring, etc.).	Establish research guidelines re working with African and Caribbean people and communities, guidelines should promote community involvement from beginning to end, and foster participation and ownership of the research process. Work with other organizations to establish processes for community-based groups to obtain ethics approval for non-university/hospital based research.

DIRECTIONS	SUGGESTED ACTIVITIES	
	Short-Term	**Mid-Term**
Promote access and adherence to drug therapies and treatments by reducing barriers related to culture and/or language.	Develop resources to support teaching regarding drug therapies and treatments (e.g. pictograms, plain language materials, interpretation services, translation of existing resources, etc.) so the most current information is available and accessible to African and Caribbean people and communities.	Look to other sectors for models/ideas (e.g. drug therapy with seniors).

Next Steps - The African and Caribbean Council on HIV/AIDS in Ontario (ACCHO)

Having completed its task of developing the Strategy, the HETF recognized the need to evolve into a permanent coalition/council with an expanded membership and a mandate geared to facilitating effective and timely implementation of the Strategy. Interim terms of reference (TORs) for the African and Caribbean Council on HIV/AIDS in Ontario (ACCHO) were drafted and recruitment of members has begun.

It is important to note that the current terms of reference for ACCHO are interim. They will be reviewed, revised as needed and approved by the full ACCHO membership at the end of its 2-year transition/start-up period. A complete copy of ACCHO's Interim Terms of Reference is attached as Appendix 3.

The African and Caribbean Council on HIV/AIDS in Ontario (ACCHO) is beginning the work of implementing this Strategy. ACCHO envisions for African and Caribbean communities in Ontario an environment supportive of those infected and affected by HIV & AIDS, and free of new HIV transmissions. ACCHO's goals are to

- ⇒ coordinate Strategy development, implementation, revision/renewal, and monitoring and evaluation;
- ⇒ develop and synthesize knowledge and policy, and set priorities to support the implementation of the Strategy and the vision of ACCHO;
- ⇒ support the work of agencies in implementing the Strategy; and
- ⇒ develop and maintain the effectiveness and relevance of ACCHO through initiatives such as organizational development, and ongoing monitoring and evaluation of ACCHO's membership and activities.

If you are interested in working with ACCHO 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

Conclusion

This Strategy is intended to provide a framework that will enhance the capacity of groups, agencies and community members to reduce the incidence of HIV among people in Ontario from countries where HIV is endemic (i.e. African and Caribbean communities), and to improve the quality of life for those infected and affected by HIV/AIDS. The Strategy attempts to outline a roadmap for the future, to set some directions and suggest activities, and to address some of the issues and challenges related to HIV that are faced by African and Caribbean people and communities.

Appendix 1: Summary of Findings of *The HIV/AIDS Epidemic Among Persons From HIV-Endemic Countries In Ontario, 1981-2002*

Robert S. Remis, Maraki Fikre Merid
University of Toronto

In November 1999, we analyzed available data and carried out statistical modeling to characterize the HIV epidemic among persons living in Ontario who were born in countries of the Caribbean and sub-Saharan Africa (HIV-endemic regions) historically and as of December 1998. We recently revisited this study and reran the analytic models using updated data on immigration, births and deaths to 2002 and updated "target" values. We also modified our analytic technique by integrating lessons learned from modeling of mother-infant HIV transmission carried out since the initial study.

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 1995; this group represented 20% of AIDS cases in 2001 and 2002 compared to less than 5% before 1996. Most such cases were younger than 45 years at time of diagnosis. Furthermore, 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, though women tended to die at a younger age than men. Based on our mother-infant modeling, the majority (53%) of HIV transmissions from infected mothers to their infants in Ontario were born to women from the Caribbean or sub-Saharan Africa.

Our updated model indicates that, as of December 2002, 2,630 persons from HIV-endemic regions and residing in Ontario were living with HIV infection (1,370 from sub-Saharan Africa and 1,260 from the Caribbean). 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. The number of HIV-infected persons and HIV prevalence rates were higher for the sub-Saharan African countries. In the past few years, the average annual rate of increase of HIV prevalence approximated 13%, representing about 300 new infections each year. The estimated number of infections among persons from HIV-endemic countries is 12% higher than the 2,350 estimated for 1998. The number was substantially higher for those from sub-Saharan Africa (60% higher than the 860 estimated for 1998) but actually lower for those from Caribbean countries (1,490 estimated for 1998). The reasons for this decrease or for the lower overall number than that obtained by simple projection from 1998 are not entirely clear but are probably related to model uncertainty. Our modeled estimates were obtained using methodologies which have important limitations. Nevertheless, the estimations represented a good fit with available reported data for most countries and were consistent with HIV prevalence previously estimated for this

population. For these reasons, we are confident our results are a plausible indication of the extent of HIV infection in 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. Whereas overall prevalence rates among immigrants from these regions may not appear substantial, they are about 20-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 occur after residence is established in Canada, suggesting that a substantial proportion (20-60%, depending on the country of origin) of HIV infections are not ”imported.

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 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 (4:1 among persons from the Caribbean and 2:1 among those from Africa).

The results of this report highlight the need for epidemiological studies 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: Member Agencies of the HIV Endemic Task Force

As of October 2003

African Community Health Services
76 Gerrard Street East, 2nd Floor
Toronto ON M5B 1G6

Africans in Partnership Against AIDS
517 College Street, Suite 338
Toronto, ON M6G 4A2

AIDS Bureau
Ontario Ministry of Health
4th Floor, 5700 Yonge Street
North York, ON M2M 4K5

Black Coalition for AIDS Prevention
110 Spadina Ave., Suite 207
Toronto, ON M5V 2K4

Centre médico-social communautaire de Toronto
22 College Street
Toronto, ON M5G 1K3

Health Canada
Population & Public Health Branch
Ontario Region
4th Floor, 25 St. Clair Avenue East
Toronto, ON M4T 1M2

Rexdale Community Health Centre
8 Taber Rd.
Etobicoke, ON M9W 3A4 *(2001 only)*

Toronto Public Health
175 Memorial Park Avenue
Toronto, ON M4J 4Y6

Youth Clinical Services Inc.
1126 Finch Avenue West - #16 & 17
North York, ON M3J 3J6

Dept. of Public Health Sciences
University of Toronto
McMurrich Bldg., 4th Floor
12 Queen's Park Crescent West
Toronto, ON M5S 1A8

Women's Health In Women's Hands
Community Health Centre
2 Carlton Street, Suite 500
Toronto, ON M5B 1J3

Appendix 3: African & Caribbean Council on HIV/AIDS in Ontario Interim Terms Of Reference

As of December 2003

These Terms of Reference (TORs) are Interim – they will be reviewed, revised as needed and approved by the full ACCHO membership at the end of the 2-year transition period.

Vision Statement

The African & Caribbean Council on HIV/AIDS in Ontario envisions for African and Caribbean communities in Ontario an environment supportive of those infected and affected by HIV & AIDS, and free of new HIV transmissions.

Approved January 21st, 2003.

Goals

The goals of African & Caribbean Council on HIV/AIDS in Ontario (ACCHO) are to:

- ⇒ coordinate Strategy development, implementation, revision/renewal, and monitoring and evaluation;
- ⇒ develop and synthesize knowledge and policy, and set priorities to support the implementation of the Strategy and the vision of ACCHO;
- ⇒ support the work of agencies in implementing the Strategy; and
- ⇒ develop and maintain the effectiveness and relevance of ACCHO through initiatives such as organizational development, and ongoing monitoring and evaluation of ACCHO's membership and activities.

Transition Period

The council has grown out of the work of the HIV Endemic Task Force (HETF). The HETF has completed its task of developing the *Strategy to Address Issues Related to HIV Faced by People in Ontario From Countries Where HIV is Endemic.* These terms of reference (TORs) were drafted by the HETF with the intent of expanding its membership and mandate, and of implementing the *Strategy* as quickly and effectively as possible.

It is important to note that these TORs are interim. They are to be reviewed, revised as needed and approved by the full ACCHO membership at the end of the 2-year transition period.

Membership

Rationale for Membership Structure and Criteria of ACCHO

To facilitate work and decision making the council will have a maximum of 21 members, of which 18 are voting members. Working groups and subcommittees with expanded memberships will be created as needed. To maximize the range of experience/expertise on ACCHO, groups or organizations can only have 1 member at a time on the council.

The goal of ACCHO's membership structure is to ensure that community members retain control of ACCHO and drive the implementation of the Strategy. Consequently, two thirds or more of the 18 voting members on the council must be Black African and Caribbean people – (i.e. 12 or more), a minimum of 7 being Black women and 5 being Black men. This is much more than a "representational" requirement; ACCHO members must meet the membership criteria and have a strong commitment to moving the issues forward. Federal, provincial and municipal government representatives sit on ACCHO as ex-officio, non-voting members.

Membership Criteria

Ideally, all ACCHO members must meet the following criteria:

- ⇒ 3 to 4 years of experience in the areas of HIV, health care, settlement & immigration, and/or community work with African and Caribbean communities in Ontario;
- ⇒ an understanding of African and Caribbean communities in Ontario and the cultural values, beliefs and norms that drive the HIV epidemic;
- ⇒ a commitment and desire to work with others, and recognition of the importance of the issue of HIV in African and Caribbean communities in Ontario; and
- ⇒ demonstrated leadership qualities.

In select cases, members who bring a critical perspective to the table (e.g. youth, people living with HIV/AIDS, private sector representatives) may not have to fulfill ***all*** of the above membership criteria.

Membership Structure

ACCHO's membership structure also strives to ensure that a full spectrum of experiences and perspectives are brought to the table. Consequently, the council has the following designated memberships:

- ⇒ a minimum of 2 Black PLWHA – one woman, one man (whenever possible one to be Caribbean and one African);

- ⇒ a minimum of 1 person from Ottawa;
- ⇒ a minimum of 1 Black youth (25 years or younger);
- ⇒ a minimum of 1 Black man who has sex with men[8] (MSM); and
- ⇒ a minimum of 1 Black French speaking person.

In addition, ACCHO has the following designated agency/organizational memberships:

- ⇒ minimum of 6 community based organizations working with African and Caribbean communities in Ontario (i.e. ethno-specific organizations, AIDS service organizations (ASO), settlement agencies, community health centres, etc.); of these a minimum of 2 must be ASOs mandated to work with Black African and Caribbean communities; 1 must be a youth organization working with African and Caribbean communities in Ontario; and 1 must be a women's organization working with African and Caribbean communities in Ontario;
- ⇒ minimum of 1 strategic partner from the private sector that can provide a link back to African and Caribbean community leaders (e.g. Black Business & Professional Association, Black Health Alliance);
- ⇒ minimum of 1 strategic partner from a social service agency working with African and Caribbean communities in Ontario;
- ⇒ minimum of 2 ethno-cultural organizations doing service delivery with African and Caribbean communities in Ontario (i.e. cultural, recreational, faith-based);
- ⇒ minimum of 1 institution/hospital/HIV out-patient clinic;
- ⇒ minimum of 1 researcher with links to a number of other researchers and institutions and networks (e.g. university based, member of CAHR and Association of HIV/AIDS Researchers of Ontario (AHRO); and
- ⇒ minimum of 1 federal, 1 provincial and 1 municipal government representative that supports, funds and/or develops policy regarding HIV and African and Caribbean communities in Ontario – as ex-officio, non-voting members.

Selection Process & Term of Membership

Transition Period

To ensure continuity current HETF member agencies will automatically become members of the council for a 2-year transitional period. During the transition period current ACCHO members will recruit people who meet the membership criteria, and can

[8] MSM is defined as gay or bisexual men, or men who have sex with men who do not self-identify as being gay or bisexual.

fill the required membership slots. Those who have previously expressed interest in joining the HETF and who meet the membership criteria will be given priority.

At the end of the first year of the transition period, ACCHO will use lessons learned from its ongoing work, its recruitment process and the expertise of its expanded membership to develop an appropriate selection process for ACCHO members in the long term (i.e. one or more processes such as: open call with applications, nomination, appointment, membership-base, etc.).

To maintain corporate history and continuity, half of the ACCHO membership slots will be opened to new members at the end of the 2-year transition period. The other half will be opened one year later. From then on half of the ACCHO membership slots will be opened every two years.

Terms on the ACCHO are two years. Members can serve a maximum of 2 consecutive terms after which there must be a minimum of a 2-year lapse before they can serve on the ACCHO again.

Accountability

ACCHO members are accountable to each other; to the staff, board and/or membership of their own organizations; to the community; and to funders where applicable.

Individual members are expected to speak from their own experience and whenever possible from that of others in their community; they come to the table as individuals.

Agency or group-based members are at the table as organizations, thus they are expected to speak for their organization and to bring an organizational commitment to the ACCHO.

Consistent representation (i.e. the same person) by agencies/groups is preferred. In the case of representation by an alternate it is expected that they come to the meeting well briefed and with the required documentation, and that the alternate be the same person whenever possible.

If a member of ACCHO fails to honor the vision and goals of ACCHO, does not fulfill their membership responsibilities and/or consistently refuses to abide by the ground rules their membership can be terminated. To terminate a member two thirds of the voting members present at a meeting must vote for termination. In the case of agency-based members, ACCHO reserves the right to request an alternate agency representative or to terminate the agency's membership.

Ground Rules, Decision Making & Quorum

ACCHO members are asked to abide by the following ground rules:

- ⇒ Everyone share/participate & listen
- ⇒ Be respectful & friendly
- ⇒ Be concrete & specific
- ⇒ Be focused & respect timelines
- ⇒ Be self-limiting regarding the amount time you speak
- ⇒ Complete tasks between meetings and come to meetings prepared

The ACCHO strives for consensus (i.e. “you can live with the decision/idea”). If the group cannot achieve consensus members must agree on a process to deal with the outstanding issue (e.g. vote, continue discussion, do further research, table the issue to another meeting, etc..).

A minimum of fifty percent plus one of the voting ACCHO members is required for quorum/decision making – i.e. 10 voting members.

Frequency of Meetings

The ACCHO meets monthly. Members are expected to complete tasks between meetings and/or to participate on ACCHO working groups or subcommittees as needed.

Members are expected to notify the meeting coordinator as soon as possible if they are unable to attend a meeting.

Documentation

Members are expected to forward agenda items to the meeting coordinator no later than 1 week before a meeting.

The meeting coordinator will circulate a draft agenda and the minutes of the last meeting at least two weeks prior to an upcoming meeting.

Members are responsible for informing themselves about meetings they miss by reading minutes and/or having discussions with other ACCHO members.