# **HIV/AIDS** and **Indigenous Peoples:**

# Final Report of the 5<sup>th</sup> **International Policy Dialogue**

International Affairs Directorate, Health Canada

October 21-23, 2009 Ottawa, Canada



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#### **LIST OF ACRONYMS**

AI/AN American Indian/Alaska Native

AIDS Acquired Immunodeficiency Syndrome

ASO AIDS Service Organization

GFATM Global Fund to Fight AIDS, Tuberculosis and Malaria

GIPA Greater Involvement of People Living With HIV and AIDS

HAART Highly Active Anti-Retroviral Treatment

HC Health Canada

HCV Hepatitis C Virus

HIV Human Immunodefiency Virus

IASG Interagency Support Group to UNPFII

IDU Injection Drug Use

ILO International Labour Organization

MDG Millennium Development Goals

MSM Men Who Have Sex with Men

NGO Non-Governmental Organization

PAHO Pan-American Health Organization

PHA People Living with HIV and AIDS

SDOH Social Determinants of Health

STBBI Sexually-Transmitted and Blood-Borne Infection

STI Sexually-Transmitted Infection

UNAIDS Joint United Nations Programme on HIV/AIDS

UNDRIP United Nations Declaration on the Rights of Indigenous Peoples

UNPFII United Nations Permanent Forum on Indigenous Issues

WHO World Health Organization

#### 1.0 EXECUTIVE SUMMARY

The relationship between HIV and indigenous peoples has not received due international attention, despite the fact that indigenous peoples have particular vulnerabilities to acquiring HIV. To provide an opportunity for international discussion and the development of policy recommendations on the topic, Health Canada, in collaboration with the Public Health Agency of Canada and the Joint United Nations Programme on HIV/AIDS (UNAIDS), hosted an International Policy Dialogue on HIV/AIDS and Indigenous Peoples in Ottawa, Canada, October 21-23, 2009.

Through panel presentations, plenary discussion and break-out sessions, participants discussed the unique impact of HIV/AIDS on indigenous peoples, its relevance to global policy development, and explored ways forward in terms of research, policy and programme development. A broad range of perspectives were represented, with participants from New Zealand, Australia, North, Central and South America, from HIV/AIDS and indigenous peoples' communities/networks, and from both government and non-governmental organizations.

A number of themes served as a foundation for the dialogue, including social determinants of health (SDOH), human rights, and the better integration of indigenous people into the international response to HIV and AIDS.

#### **SOCIAL DETERMINANTS OF HEALTH AND HIV/AIDS**

The experience of indigenous peoples in responding to HIV/AIDS must be considered in the broader context of colonization and historical and persistent marginalization, a central underlying cause of many existing health disparities between indigenous and non-indigenous peoples.

Specific HIV/AIDS risk factors and the underlying structural and social drivers that increase the vulnerability of indigenous populations to HIV/AIDS were identified, and include: poverty, marginalization, lack of political and social power, fragmentation of family and community relationships, geographical isolation, low literacy rates, poor general health, limited access to health care, drug use/injection, and low individual and community self-esteem.

The multiple social and structural factors dictate that those working in areas of health outside of HIV/AIDS be engaged in identifying solutions, as well as those working in non-health sectors, such as poverty, education, housing, justice and employment. Participants discussed the importance of prioritizing the indigenous determinants of health that have the greatest potential to drive policy change. Key identified areas included addressing the root causes of poverty and addressing stigma and discrimination, including the double stigma experienced by indigenous peoples living with HIV/AIDS.

#### INDIGENOUS PEOPLES' HUMAN RIGHTS AND THE HIV RESPONSE

Over time, indigenous peoples have fought to maintain their economic, political, social, cultural and land rights in the face of discrimination, acculturation, appropriation and marginalization. Dialogue discussion highlighted the importance of using a human rights-based framework to

affirm both the value and strengths of indigenous cultures, as well as to reinforce claims for universality, equality and dignity. The United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP) and other international instruments, such as the International Labour Organization's Convention  $169^1$ , formally recognize the rights of indigenous peoples. However, there is a need to move beyond ratification of these treaties to action by international bodies, governments, and civil society.

#### GLOBAL HIV/AIDS RESPONSE AND INDIGENOUS PEOPLES

There was consensus at the dialogue that, to date, the realities and voices of indigenous peoples have not been well integrated into the global HIV/AIDS agenda. In addition to the dialogue there have been some key efforts, however, including:

- Satellite sessions at recent International AIDS Conferences, where indigenous peoples have discussed the impact of HIV/AIDS on their communities. Participants of the Indigenous Satellite at AIDS 2006 developed the Toronto Charter, outlining key principles and recommendations of an Indigenous Peoples' Action Plan on HIV/AIDS;
- Recommendations by the UN Permanent Forum on Indigenous Issues (UNPFII) to promote the better integration of indigenous peoples into the HIV/AIDS response;
- A report by the Joint United Nations Programme on HIV/AIDS identifying leadership and advocacy actions to reduce the impact of HIV on indigenous communities; and
- A focus on "Indigenous Peoples and HIV/AIDS" for the 2009 International Day of the World's Indigenous Peoples, calling on governments and civil society to act with urgency to improve indigenous peoples' access to the information and infrastructure necessary for HIV/AIDS detection, treatment and protection.

#### **KEY DISCUSSION THEMES**

#### **MODES OF TRANSMISSION**

According to available data, transmission follows a different pattern for indigenous peoples than it does for the general population. There is also a different pattern of transmission for indigenous men and women. Modes of transmission vary between countries in the North and South, and within these regions. Identified trends included:

- A higher proportion of new HIV diagnoses among indigenous peoples;
- High rates of HIV transmission by injection drug use (IDU) in developed countries;
- Men who have sex with men (MSM) as the most common mode of transmission in most developed countries;
- High rates of HIV transmission among indigenous women, particularly in developing countries; and.

<sup>&</sup>lt;sup>1</sup> International Labour Organization Convention 169 on Indigenous and Tribal Peoples, adopted in Geneva, June 1989. Available at: http://www.ilo.org/ilolex/cgi-lex/convde.pl?C169

 A younger age of HIV infection of indigenous peoples compared to the non-indigenous population in some countries.

#### POLITICAL GEOGRAPHY

Dialogue participants discussed how aspects of the political geography in their regions have impacted their vulnerability to HIV infection and their communities' response to the epidemic. In some regions, government policies have forced the migration and displacement of indigenous peoples from their traditional territories for the purposes of land development or resource extraction, disrupting traditional economies and impacting HIV transmission. Men forced to find work away from their home territory may become exposed to HIV and may transmit the infection to women in their communities upon their return home. Similarly, forced dislocation has led some indigenous women to large urban centres where they may turn to sex work to support their families, thereby increasing their risk of HIV infection. Diversity of languages and cultures, the physical distance between small, remote communities, and high levels of mobility present challenges for HIV/AIDS prevention, testing, treatment and support amongst indigenous peoples.

#### **GENDER IDENTITIES AND SEXUAL DIVERSITY**

Many indigenous cultures have traditionally understood sexuality as rooted in holistic world views, where sexuality is a part of creation, connected to their ancestry and cultural traditions, the cycle of life, and their natural environment. In some indigenous cultures, sexual diversity was historically accepted and celebrated. However, colonization has had a significant impact on sexuality among indigenous peoples. Participants discussed how some indigenous communities are making efforts to reclaim their traditional understandings of healthy sexuality. They also discussed, however, the stigma and discrimination that exists in many indigenous communities, and more broadly, against gay, lesbian, bisexual, transgendered and two-spirited persons, calling for a shift to greater acceptance and understanding to ensure that all peoples are visible and have equitable access to HIV prevention, testing, treatment and support services.

#### INDIGENOUS WOMEN AND HIV/AIDS

Participants affirmed that women and girls face widespread racialized, sexualized violence. Violence and trauma experienced by indigenous women has its roots in colonization. As a result of colonization indigenous women experienced conflict, rape as a weapon of war, the breakdown of healthy family structures, and the loss of women's traditional cultural role and authority. These acts, along with other forms of verbal, physical and sexual violence perpetuate feelings of powerlessness that can increase vulnerability to HIV infection. As part of their daily survival strategies, some indigenous women trade unsafe sex for money, food, shelter, or drugs, share needles, or have unprotected sex when under the influence of drugs. Participants talked about the importance of empowering indigenous women to speak about their own experiences with HIV/AIDS. They also discussed examples of approaches that involve indigenous men and boys in order to shift negative perceptions of gender roles and to contribute to the prevention of violence against women in their communities.

#### INDIGENOUS YOUTH AND HIV/AIDS

Many indigenous populations are experiencing population growth, with a higher proportion of children and youth in their communities than in the past. At the same time as the younger generation is growing, rates of HIV infection among indigenous youth are also increasing. Participants discussed how adults can best support indigenous youth to respond to the HIV epidemic and the value of youth-to-youth peer education and support. Traditional knowledge and youth culture are central to approaches to HIV/AIDS prevention and support programs. International bodies, national governments and civil society need to support and engage youth and promote the passing on of indigenous languages, cultures and traditions from elders.

#### TRADITIONAL AND WESTERN MEDICINES

Participants discussed the sacred nature of traditional medicines and the importance of protecting them from appropriation and commercialization, as well as maintaining indigenous autonomy and choice of medicines. The discussion encompassed indigenous peoples' right to health and to services that respect their language, culture and traditional healing practices. Participants shared practical examples of cooperation between traditional and Western medicines and talked about efforts to develop policies that support the use of traditional medicines and healing practices to treat HIV.

#### SUBSTANCE USE AND MENTAL ILLNESS

Substance use and mental health problems can increase the vulnerability of indigenous peoples to HIV/AIDS, with some countries observing higher rates of substance use and mental health problems among indigenous peoples than among the non-indigenous population. Colonization is seen as an important underlying cause of both substance use and mental health problems among a large percentage of indigenous peoples because of its destructive effect on the social fabric and traditions of their communities. Participants discussed the importance of: using approaches to treat substance abuse for indigenous peoples that address the underlying causes; using a holistic health approach grounded in cultural traditions; combating stigmatization and breaking the cycle of shame and blame; having open dialogue about sex and healthy sexuality; and addressing co-infection of HIV, Hepatitis C virus and other sexually transmitted and blood-borne infections.

#### **CO-INFECTION**

Rates of tuberculosis (TB), Hepatitis C Virus (HCV) and sexually-transmitted infections (STIs) are higher among indigenous peoples than non-indigenous peoples, with data from a number of countries indicating increasing rates of TB, HCV and STIs among indigenous peoples. The risk of HIV infection is five times greater with the presence of co-infection, which weakens the body's barriers to the virus. The presence of STIs is also a marker for unsafe sexual practices and therefore increased risk of infection. A range of approaches were identified to strengthen prevention and treatment of HIV co-infections among indigenous peoples, such as: supporting the development of community-specific, culturally-relevant programmes that increase community control over their health; taking action on the underlying social and economic determinants; providing funding support for co-infection approaches; and combining HIV and STI, HCV and TB counselling and testing, where appropriate, to increase screening rates.

#### RESEARCH, SURVEILLANCE AND DATA COLLECTION

Participants discussed the limitations of current systems for surveillance and data collection, noting how indigenous peoples are often invisible in reported statistics. Discussion focused on the importance of working toward disaggregated data that can support a more equitable and effective HIV response for indigenous peoples. Participants also discussed a range of issues that are barriers to collecting disaggregated data, including: the impact of stigma and cultural taboos; the importance of involving indigenous communities and PHAs in research, data collection, analysis and sharing of information; and the need for capacity-building to support research, policy and programme development.

#### **OPPORTUNITIES FOR POLICY AND PROGRAMMATIC RESPONSE**

In order for meaningful change to occur, there is a need for action at both the international and national levels. Participants discussed how best to leverage international policy instruments, such as the UNDRIP and ILO Convention 169, calling for the creation of operational tools that can be used to hold states accountable for ensuring equitable access of indigenous peoples to culturally-appropriate and culturally-relevant HIV/AIDS prevention, testing, treatment and support. Strategic roles for the UNPFII, UNAIDS and the UN Special Rapporteur on the Right to Health were discussed in order to identify indigenous peoples as a priority group in the HIV/AIDS response, to influence states to develop national strategies for HIV/AIDS and indigenous peoples, and to advocate for AIDS service organizations to develop culturally-appropriate, culturally-relevant services for indigenous peoples in partnership with indigenous communities' representatives. Participants also identified the need for capacity-building to meaningfully involve indigenous peoples and persons living with HIV/AIDS in the indigenous HIV response at the research, policy and programmatic levels.

#### **RECOMMENDATIONS FOR ACTION**

Early in the dialogue, participants expressed a strong desire to identify concrete actions to make a tangible difference for indigenous communities around the world. Participants, therefore, developed the following recommendations aimed at building upon the past advocacy efforts of indigenous peoples and further influencing action at the global, country and local levels. They also identified a mechanism for sustaining their efforts beyond the three-day dialogue.

In some cases, the recommendations are directed at specific organizations. Most often, however, the recommendations are directed broadly at the global community, to integrate into its work in the areas of research, policy and programme development.

#### RECOMMENDATION 1: SUPPORT THE INTERNATIONAL INDIGENOUS PEOPLES WORKING GROUP ON HIV/AIDS

During the indigenous caucuses at the Dialogue, indigenous participants established and formally endorsed an International Indigenous Peoples Working Group on HIV/AIDS (IIHAWG):

"The IIHAWG recommends that the Canadian Aboriginal AIDS Network (CAAN) continue its leadership role in convening meetings of the working group and that CAAN seek support to convene the Working Group with support of the Federal Initiative, and that CAAN continue the work started this week by organizing preparations for indigenous participation before the international AIDS conference in Vienna 2010, participation in Vienna and beyond Vienna."

Moved: Clive Aspin, New Zealand Seconded: Michael Costello, Australia

Carried unanimously October 22, 2009

The creation of the IIHAWG represents the most significant, direct, immediate action arising from the three-day dialogue. Many participants expressed the belief that the IIHAWG could provide a unified voice for indigenous peoples and a structure for collective action.

#### RECOMMENDATION 2: PROMOTE THE RIGHTS OF INDIGENOUS PEOPLES IN RELATION TO HIV/AIDS

Participants called for the acknowledgement of the root causes of HIV/AIDS among indigenous peoples and for advocacy toward a human-rights based approach to achieving the Millenium Development Goals they identified. A range of recommendations aimed at ensuring that the rights of indigenous peoples are understood and respected by international bodies, national governments, non-governmental organizations and civil society.

### RECOMMENDATION 3: RESPECT INDIGENOUS PEOPLES' UNDERSTANDING OF SEXUAL AND GENDER DIVERSITY AND HEALTHY SEXUALITY

Participants recommended using inclusive language that names all sexual and gender identities, including gay, lesbian, bisexual, transgendered, and two-spirited, and promoting the use of indigenous language describing sexual diversity and indigenous understandings of healthy sexuality. They also suggested that strategies be developed to reduce stigma and combat homophobia, both within indigenous communities and within broader society.

#### RECOMMENDATION 4: INTEGRATE HIV/AIDS AND INDIGENOUS PEOPLES ISSUES AT THE INTERNATIONAL LEVEL

Participants called for international bodies to build an effective HIV/AIDS policy and programmatic response that takes into consideration indigenous peoples' understanding of health and traditional health practices. They recommended that UNPFII include this dialogue report on its next agenda for official response. They also recommended that UNPFII and the IIHAWG lobby UNAIDS to: identify indigenous peoples as a priority group; call for countries to develop national strategies for HIV/AIDS and indigenous peoples; and to advocate for AIDS

service organizations to develop culturally-appropriate, culturally-relevant services for indigenous peoples, in partnership with indigenous representatives.

#### RECOMMENDATION 5: Build Capacity to Integrate HIV/AIDS and Indigenous Peoples' Issues

In order to better integrate indigenous peoples' issues into the HIV/AIDS response, indigenous participants recommended that and HIV/AIDS non-governmental organizations/networks, supported by international bodies such as UNAIDS, take an active role in ensuring that their countries develop a national strategy and workplan for HIV/AIDS and indigenous peoples; commit to indigenous-specific public health programmes that are culturally-appropriate and culturally-relevant; and consider training indigenous public health officers to hold salaried positions in national health services. Other recommendations to increase capacity related to increasing project funding for HIV/AIDS and indigenous peoples through the Global Fund for HIV/AIDS, Tuberculosis and Malaria and urging HIV/AIDS funding bodies to require inclusion of indigenous communities, gender and ethnicity in development processes as part of application criteria.

#### RECOMMENDATION 6: FACILITATE SHARING OF KNOWLEDGE AND WISE PRACTICES

Participants recommended putting in place a range of formal and informal mechanisms to facilitate an exchange of knowledge and wise practices, including that all dialogue participants share formal policy papers and evaluation reports through their informal networks. They suggested that a synthesis be completed and shared of the indigenous satellite meetings held in conjunction with recent International AIDS Conferences (i.e. Toronto, Mexico) and that examples of successful cooperation between Western and traditional medicine to support indigenous PHAs be documented. These actions will help to increase recognition and support for the important role of traditional medicine in the response to HIV/AIDS among indigenous peoples.

## RECOMMENDATION 7: Ensure Meaningful Involvement of Indigenous Peoples in Research, Policy and Programme Development Related to HIV/AIDS

Participants recommended better cooperation between indigenous peoples, governments and organizations, with indigenous peoples supported and engaged in identifying the needs of their communities, identifying solutions and implementing policies and programmes. They suggested that indigenous caucus meetings be included on the agenda of all future fora related to indigenous issues, and that these be used to help build the skills, experience, and knowledge of indigenous peoples and PHAs to participate meaningfully at every stage of research, policy and programme development processes. They called for expanded opportunities for the involvement of indigenous PHAs within national HIV/AIDS movements, in order to influence policy and programme development and for the development and distribution of guidelines on overcoming barriers to indigenous participation.

#### RECOMMENDATION 8: Ensure Accurate Representation of Indigenous Peoples in HIV/AIDS Data

Participants recommended sensitizing national governments about rates of HIV/AIDS among indigenous peoples and urging UNAIDS to remind countries to recognize indigenous peoples as high risk populations in their national UNGASS reports. They called for all parties to support, enhance and participate in efforts to create internationally comparable indigenous HIV/AIDS indicators, aiming for disaggregated data for population sub-groups (e.g., gender, age, indigenous/ethnic group, route of HIV transmission) and suggested the sharing of good examples of sophisticated surveillance methods, data collection tools, analysis and reporting, including monitoring co-infections, and their application to support policy and programme decisions.

#### RECOMMENDATION 9: PROMOTE THE USE OF AN INDIGENOUS SOCIAL DETERMINANTS OF HEALTH APPROACH

Participants recommended expanding dialogue and understanding of SDOH to include determinants identified by indigenous peoples, engaging key indigenous and non-indigenous health stakeholders (e.g., HIV/AIDS, sexually transmitted and blood borne infections, tuberculosis, diabetes) and non-health sector stakeholders (e.g., poverty, education, housing, environment, etc) in identifying and implementing solutions. They also suggested convening a policy dialogue between indigenous community health workers and multiple SDOH sectors to build capacity to apply an indigenous-specific SDOH approach to the HIV/AIDS response.

#### **RECOMMENDATION 10:** Increase Youth Involvement in the HIV Response

Participants recommended providing support for indigenous youth participation in HIV/AIDS research, policy and programme development, linking HIV/AIDS programmes for indigenous youth to arts and cultural programmes, and encouraging adults in organizations and tribal leaders in the community to serve as allies to youth. They called for a redesign of HIV prevention approaches and materials for youth that move away from abstinence-only prevention approaches that are widely seen to be ineffective, toward treatment and support resources that are holistic and culturally-relevant, including options for mobile access for youth in rural, remote locations.

#### 2.0 BACKGROUND

The relationship between HIV and indigenous peoples has not received due attention, despite the fact that indigenous peoples have particular vulnerabilities to acquiring HIV. The Joint United Nations Programme on HIV/AIDS (UNAIDS) states that key risk factors that render individuals and communities acutely vulnerable to HIV are present in large numbers of indigenous populations around the world.<sup>2</sup>

To date there has been limited opportunity for international discussion on these risks, limiting the scope of critical analysis, debate, and discussion on policy objectives for the way forward. Health Canada's International Affairs Directorate, in consultation with the First Nations and Inuit Health Branch and the Public Health Agency of Canada, identified the need for an in-depth discussion of the unique impact of HIV/AIDS on indigenous peoples, and its relevance to global policy development.

In collaboration with the Public Health Agency of Canada and the Joint United Nations Programme on HIV/AIDS (UNAIDS), Health Canada hosted an International Policy Dialogue on HIV/AIDS and Indigenous Peoples in Ottawa, Canada, October 21-23, 2009. The dialogue provided a forum for key stakeholders to come together to discuss the impact of HIV/AIDS on indigenous peoples, and to explore a way forward in terms of research, policy and programme development.

An advisory committee developed the meeting agenda and the dialogue process, and identified presenters and participants. The members of the advisory committee are listed in Appendix A. Health Canada worked with the advisory committee to prepare a background paper, which was informed by a human rights based approach. The paper identified that, at its root, the impact of HIV/AIDS on indigenous peoples relates to colonization, racism, oppression, resource alienation, and systemic exclusion from research, policy, and programme decisions that impact health and well-being. The research paper was circulated before the meeting, outlining emerging issues related to indigenous peoples and HIV/AIDS.

### 5<sup>TH</sup> INTERNATIONAL POLICY DIALOGUE: HIV/AIDS AND INDIGENOUS PEOPLES

Approximately 50 stakeholders participated in the three-day dialogue. A broad range of perspectives was represented, with participants from New Zealand, Australia, North, Central and South America, from HIV/AIDS and indigenous peoples' communities/networks, and from both government and non-governmental organizations. Participants brought a range of experiences to the dialogue, including community advocacy, education/awareness-building, service provision, policy and programme development, and research. The list of participants is included in Appendix B.

The objectives of the policy dialogue were to:

Raise awareness of the issues and evidence related to HIV/AIDS and indigenous peoples;

<sup>&</sup>lt;sup>2</sup> UNAIDS Report on the Millennium Development Goals and Indigenous Peoples – Redefining the Goals, March 2006 http://data.unaids.org/pub/Report/2006/unaidsindigenousissuespaper en.pdf

- Foster knowledge transfer amongst indigenous peoples, policy makers, programme developers, and researchers via the sharing of lessons learned and wise practice models for translating these lessons into effective policies and programmes;
- Develop/strengthen relationships that will link those involved in HIV/AIDS with the global indigenous health community, in order to inform and enhance both domestic and global responses to HIV/AIDS amongst indigenous peoples; and
- Identify gaps and areas where further education, policy development, programming, and research are necessary, identifying next step recommendations.

Indigenous peoples and persons living with HIV/AIDS (PHAs) participated as representatives of their communities, networks or organizations. They also shared their personal experiences to enrich the dialogue and to give voice to both the challenges they face and their abilities as indigenous peoples and PHAs to provide leadership and solutions. Two indigenous peoples' caucuses were organized during the three-day session. A First Nations, Inuit or Métis elder opened each daily session with a blessing.

By bringing together indigenous peoples and HIV/AIDS experts from around the globe, the dialogue was able to support an exchange of knowledge and experience on emerging issues for indigenous peoples in HIV/AIDS research, policy and programme development. Representatives from international bodies, state governments and non-governmental networks were able to learn from the experience of indigenous peoples and collaborate with indigenous leaders in recommending meaningful actions and practical next steps for HIV/AIDS prevention, treatment, care and support.

#### 3.0 OVERVIEW OF THE DIALOGUE PROCESS

The meeting agenda and biographies of presenters are included in Appendices C and D. The dialogue process was facilitated by consultants from One World Inc. to help participants share knowledge, build relationships, and exchange experiences and ideas to advance their work.

This report presents highlights of the dialogue, drawing from the following elements:

- The background paper circulated to all participants in advance of the dialogue, which outlined emerging issues and relevant policy developments in the area of HIV/AIDS among indigenous peoples;
- The opening key-note address by Chief Wilton Littlechild, Commissioner of the Truth and Reconciliation Commission, which focused on human rights of indigenous peoples, the right to health, and the use of international instruments and global fora to leverage policy action for prevention and treatment of HIV/AIDS among indigenous peoples;
- A series of panel sessions and presentations on various topics, followed by question/answer periods, to provide context and stimulate discussion (see Appendix C – Meeting Agenda);
- Break-out discussions in small groups, which focused on emerging issues in the area of HIV/AIDS and indigenous peoples; and

Two indigenous peoples caucuses, from which there were reports back to the plenary.

A summary of key issues and recommendations were generated throughout the three days of discussions. This summary served as the foundation for the concluding discussion on recommendations and next steps at the global, regional and national levels on HIV/AIDS and indigenous peoples in the areas of education/awareness, programming, policy development and research.

#### 4.0 GLOBAL CONTEXT – INDIGENOUS PEOPLES AND HIV/AIDS

#### 4.1 SOCIAL DETERMINANTS OF HEALTH AND HIV/AIDS

There are inextricable links between protecting human rights, promoting health, and preventing HIV infection. These links can be understood by taking into account the complex interactions between social and economic factors, health systems, the physical environment and individual behaviour. With regard to HIV/AIDS, these determinants of health can affect access to relevant information and outreach education, access to testing as well as the willingness to be tested, availability and types of treatment, and care, and risks of infection.

UNAIDS states that key risk factors that render individuals and communities acutely vulnerable to HIV are present in large numbers of indigenous populations worldwide. Risk factors include:

- Lack of political and social power;
- Fragmentation of family and community relationships;
- Gender inequalities;
- Socio-economic disadvantage including poverty, lower education standards and subsequent lower health literacy;
- Low individual and community self-esteem;
- Cultural and language diversity, dispersion and remote location of some communities, which limit HIV prevention activities and access to health services;
- Stigma and discrimination relating to race, sexuality and HIV status; and
- A much younger and more mobile population compared to the non-indigenous population.

UNAIDS has highlighted the importance of these structural and social drivers of the HIV/AIDS epidemic. Many of these factors are not easily measured, but they increase indigenous peoples' vulnerability to HIV infection and create disparities in health and access to health services.<sup>3</sup> In addition, because these factors lie primarily outside of the health sector, multi-sectoral action is required at the policy level to address structural and social drivers.

Disparities like poverty, low literacy or limited access to health care are not conditions that indigenous peoples face exclusively. However, the experience of indigenous peoples in

<sup>&</sup>lt;sup>3</sup> UNAIDS, "Drivers of the Epidemic", <a href="http://www.unaids.org/en/PolicyAndPractice/DriversOfTheEpidemic/default.asp">http://www.unaids.org/en/PolicyAndPractice/DriversOfTheEpidemic/default.asp</a> [Retrieved March 2009]

responding to HIV/AIDS must be considered in the broader context of colonization and historical and persistent marginalization, central underlying causes of many existing health disparities between indigenous and non-indigenous peoples. The dynamics of how specific HIV/AIDS risk factors, as well as underlying drivers, uniquely impact on indigenous populations and increase HIV/AIDS susceptibility are complex, and are discussed throughout this report.

#### 4.2 INDIGENOUS PEOPLES RIGHTS AND THE HIV RESPONSE

The health and well-being of indigenous peoples cannot be separated from ensuring that all rights are recognized, respected and protected. This includes consideration of the right to health, as well as the impact of detachment from ancestral lands on cultural identity and traditional ways of life that support economic livelihoods and sustain health and well-being.

On September 13, 2007, the United Nations General Assembly adopted the United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP) following more than twenty years of discussion, throughout which indigenous representatives played a key role. The pre-amble of the UNDRIP, ratified by 143 countries in 2007, speaks directly to protecting and promoting the cultural distinctiveness of indigenous peoples and the rich contribution of indigenous knowledge, traditions and practices to all humankind.

Over time, indigenous peoples have fought to maintain their economic, political, social, cultural and land rights against discrimination, acculturation, appropriation and marginalization. A human rights-based framework provides the ability to affirm both the special values and strengths of indigenous cultures, as well as reinforce claims for universality, equality and dignity.<sup>4</sup>

The UNDRIP and other international instruments, such as the International Labour Organization Convention 169<sup>5,</sup> formally recognize the rights of indigenous peoples.

#### 4.3 GLOBAL HIV/AIDS RESPONSE AND INDIGENOUS PEOPLES

To date, the realities and voices of indigenous peoples have not been well integrated into the global HIV/AIDS agenda. As a result, there is a serious gap in reaching some of the most vulnerable populations who need access to HIV prevention, testing, care, treatment and support. In addition, effective policy and programmatic responses need to take into consideration indigenous peoples' understanding of and approaches to maintaining health, well-being and traditional health practices.

Satellite sessions at recent International AIDS Conferences have provided a forum for indigenous peoples to discuss the impact of HIV/AIDS on their communities and to develop a call to action. At the XVI International AIDS Conference in 2006, the Toronto Charter outlined key principles and recommendations of an Indigenous Peoples' Action Plan on HIV/AIDS (see

<sup>&</sup>lt;sup>4</sup> From Background Paper, HIV/AIDS and Indigenous Peoples, prepared by Andrea S. Papan, Atlantic Centre of Excellence for Women's Health.

<sup>&</sup>lt;sup>5</sup> International Labour Organization Convention 169 on Indigenous and Tribal Peoples, adopted in Geneva, June 1989. Available at: http://www.ilo.org/ilolex/cgi-lex/convde.pl?C169

Appendix F).<sup>6</sup> The Toronto Charter is intended to address individuals who influence and make decisions about HIV/AIDS service provision for indigenous peoples, and to support agencies to develop effective and responsive programmes.

The Toronto Charter and the records of discussion at other satellite sessions have not been widely integrated into research, policy and programme decisions at the global, regional or national level. To date, key principles outlined in the Charter have not, for the most part, been respected, and recommendations have been implemented only to a limited extent in some regions.

The UN Permanent Forum on Indigenous Issues (UNPFII)<sup>7</sup> has made a series of recommendations to promote the better integration of indigenous peoples into the HIV/AIDS response. For example, UNPFII has called for the Global Fund to Fight AIDS, Tuberculosis and Malaria (GFATM) to gather and disaggregate data on children and women based on ethnicity, cultural and tribal affiliation and language; to participate in the UNPFII Interagency Support Group; and to integrate best practices for HIV/AIDS care in indigenous communities into strategies for achieving the Millennium Development Goals (MDGs).

In May 2006, in response to recommendations of the UNPFII, UNAIDS submitted a report on indigenous issues and HIV/AIDS.<sup>8</sup> The report provided an analysis of key factors influencing the vulnerability of indigenous peoples and the impact of HIV/AIDS on their communities, as well as examples of initiatives of HIV prevention among indigenous communities.

The UNAIDS report recommended that the UNPFII take leadership and advocacy actions to reduce the impact of HIV on indigenous communities, including:

- Engagement with the global movement toward universal access to HIV prevention and care;
- Participation in the development of models of HIV intervention that acknowledge the social and economic factors that affect indigenous populations;
- Advocacy for the availability of better data and information to drive HIV policy and planning in indigenous communities;
- Assistance in the development of strategies based on an understanding of indigenous culture, practices and beliefs; and
- Fostering of indigenous community participation and informed consent in policy development.

Despite these recommendations, there has been a wide and persistent gap between the recognition of the rights of indigenous peoples and their experiences living with and

<sup>&</sup>lt;sup>6</sup> The Toronto Charter is an initiative of the Planning Committee of the International Indigenous Peoples Satellite at the 16th International AIDS Conference, 2006 and has been endorsed by Indigenous People around the world. Available on-line at: http://www.afao.org.au/view\_articles.asp?pxa=ve&pxs=86&id=598#chart

<sup>&</sup>lt;sup>7</sup> The UN Permanent Forum on Indigenous Issues is an advisory body to the Economic and Social Council, with a mandate to discuss indigenous issues related to economic and social development, culture, the environment, education, health and human rights.

<sup>&</sup>lt;sup>8</sup> UNAIDS Report on the Millennium Development Goals and Indigenous Peoples – Redefining the Goals, March 2006 http://data.unaids.org/pub/Report/2006/unaidsindigenousissuespaper en.pdf

responding to HIV/AIDS. In recognition of this gap, the 2009 International Day of the World's Indigenous Peoples focused on "Indigenous Peoples and HIV/AIDS". UN Secretary-General Ban Ki-moon called on governments and civil society to act with urgency to close the implementation gap in full partnership with indigenous peoples. In his message, the Secretary-General emphasized that it was essential that "indigenous peoples have access to the information and infrastructure necessary for detection, treatment and protection".9

#### 5.0 RECOMMENDATIONS FOR ACTION

Early in the dialogue, participants expressed a strong desire to identify concrete actions that could be moved forward to make a tangible difference for indigenous communities around the world impacted by HIV/AIDS. Participants, therefore, developed the following recommendations aimed at building upon the past advocacy efforts of indigenous peoples and further influencing action at the global, country and local levels. They also identified a mechanism for sustaining their efforts beyond the three-day dialogue.

In some cases, the recommendations are directed at specific organizations. However, for the most part, the recommendations are directed broadly at the global community to take up in its work in the areas of research, policy and programme development.

#### RECOMMENDATION 1: SUPPORT THE INTERNATIONAL INDIGENOUS PEOPLES WORKING GROUP ON HIV/AIDS

During the indigenous caucuses, indigenous participants at the dialogue established and formally endorsed an International Indigenous Peoples Working Group on HIV/AIDS (IIHAWG):

"The IIHAWG recommends that the Canadian Aboriginal AIDS Network (CAAN) continue its leadership role in convening meetings of the working group and that CAAN seek support to convene the Working Group with support of the Federal Initiative, and that CAAN continue the work started this week by organizing preparations for indigenous participation before the international AIDS conference in Vienna 2010, participation in Vienna and beyond Vienna."

Moved: Clive Aspin, New Zealand Seconded: Michael Costello, Australia

Carried unanimously October 22, 2009

The creation of the IIHAWG represents the most significant, direct, immediate action arising from the three-day dialogue session. Many participants expressed the belief that the IIHAWG could provide a unified voice for indigenous peoples and a structure for collective action.

<sup>&</sup>lt;sup>9</sup>United Nations International Day of the Worlds' Indigenous Peoples, August 9, 2009 <a href="http://www.un.org/en/events/indigenous/2009/">http://www.un.org/en/events/indigenous/2009/</a>

Recommendations included the following:

- 1a. Dialogue participants recognize and support the IIHAWG in its efforts to:
  - Move the work of the dialogue initiative forward;
  - Meet yearly, beginning with preparations for indigenous participation before and during the XVIII International AIDS Conference in Vienna in 2010;
  - Support CAAN in its efforts to secure funding of its activities through Government of Canada programmes that support HIV/AIDS activities;
  - Identify additional sources of funding to support its activities; and
  - Work with indigenous representatives to develop a unified, strong voice to influence international bodies, national governments, AIDS networks and indigenous peoples networks to mobilize an immediate, well-funded and well-coordinated indigenous HIV/AIDS response.
- 1b. Develop an implementation plan that will see the IIHAWG sustained over the long term, including the identification of people and funding to support its mandate. Key elements of the implementation plan could include:
  - A proposal for funding and support of IIHAWG activities presented to UNPFII, UNAIDS and/or other international funding bodies;
  - A communications plan for sharing information within indigenous peoples' networks and exchanging contact information;
  - An advocacy plan for developing strategic partnerships (e.g., UNPFII, UNAIDS), reaching international bodies, funders, researchers, policy-makers and AIDS service networks;
  - Supporting the development of regional networks among indigenous peoples (e.g., in Australia, New Zealand and the Pacific, and in Latin America);
  - Creating opportunities to share indigenous community knowledge and experience with regards to responding to HIV/AIDS (e.g., South-South and North-South); and
  - Finding ways to identify and share wise practices among the new networks created through the dialogue (e.g., what is working well for indigenous peoples in areas of HIV/AIDS prevention, testing, treatment, care and support).

#### RECOMMENDATION 2: PROMOTE THE RIGHTS OF INDIGENOUS PEOPLES IN RELATION TO HIV/AIDS

Participants discussed the cross-cutting theme of ensuring that the rights of indigenous peoples are understood and respected by international bodies, national governments, non-governmental organizations and civil society. Over-arching recommendations included:

2a. Acknowledge the root causes of HIV/AIDS among indigenous populations, including colonisation, racism and oppression, resource alienation and systematic exclusion from research, policy and programme decisions that impact health and well-being;

- 2b. Advocate for a human rights-based approach to achieving the Millennium Development Goals that emphasizes universality, equality, participation and accountability, and that supports indigenous leadership and the right to self-determination in finding solutions to the HIV epidemic;
- 2c. Respect and include indigenous peoples' world-views, perspectives, experiences and concepts of development in future events and in all aspects of HIV/AIDS research, policy and programme development;
- 2d. Raise awareness of stigma and discrimination toward indigenous peoples, and strive to end practices of institutional racism that create and maintain health inequities;
- 2e. Advocate for ratification of the UN Declaration on the Rights of Indigenous Peoples and International Labour Organization Convention 169 as an awareness-raising tool and a platform for action;
- 2f. Develop operational tools, beyond existing international treaties and conventions, that hold state governments accountable for ensuring equitable access of indigenous peoples to culturally-appropriate and culturally-relevant HIV/AIDS prevention, testing, treatment, care and support;
- 2g. Explore the development of a pan-government indigenous lens that would outline key considerations for creating policies and programmes and assessing their appropriateness and impact on indigenous peoples (similar to several existing lenses for gender equality and the environment); and,
- 2h. Engage the Special Rapporteur on the Right to Health to influence action on HIV/AIDS and indigenous peoples at international and national levels.

### RECOMMENDATION 3: RESPECT INDIGENOUS PEOPLES UNDERSTANDING OF SEXUAL AND GENDER DIVERSITY AND HEALTHY SEXUALITY

Participants talked about the wide range of indigenous understandings of gender identities and healthy sexuality. These understandings are often rooted in a holistic world view where sexuality is a part of creation, connected to ancestry and cultural traditions, the cycle of life and the natural environment. Recommendations included:

- 3a. Use inclusive language that names all sexual and gender identities, including gay, lesbian, bisexual, transgendered, and two-spirited;
- 3b. Promote the use of indigenous language describing sexual diversity and indigenous understandings of healthy sexuality;
- 3c. Develop strategies to combat homophobia and to reduce stigma against indigenous PHAs, both within indigenous communities and within broader society; and
- 3d. Respect diverse regional approaches and priorities for ensuring sexual rights, recognizing different legal frameworks, cultural readiness (e.g., in states where criminalization of homosexuality exists) and regional priorities.

#### RECOMMENDATION 4: INTEGRATE HIV/AIDS AND INDIGENOUS PEOPLES ISSUES AT THE INTERNATIONAL LEVEL

To date, AIDS advocacy groups have been the voice for HIV/AIDS prevention and care, achieving a high level of global awareness of the impact of the epidemic. However, the realities of indigenous peoples have not been well integrated into the AIDS agenda. As a result, there is a serious gap in reaching some of the most vulnerable populations who need testing, treatment, care and support. An effective policy and programmatic response needs to take into consideration indigenous peoples' understanding of health and traditional health practices.

At the same time, international bodies working on indigenous health issues have not integrated HIV/AIDS into broader agendas focused on global development and the rights of indigenous peoples. Participants recommended an integration of HIV/AIDS and indigenous peoples' issues at the international level. They include:

- 4a UNPFII to include this dialogue report on its next agenda for official response and/or key recommendations from the dialogue should be championed by the UNPFII representative who attended the dialogue;
- 4b. UNPFII and the International Indigenous Peoples Working Group on HIV/AIDS (IIHAWG) to lobby UNAIDS to:
  - Identify indigenous peoples as a priority group
  - Call for countries to develop national strategies for HIV/AIDS and indigenous peoples
  - Advocate for AIDS service organizations to develop culturally-appropriate, culturally-relevant services for indigenous peoples, in partnership with indigenous representatives;
- 4c. UNPFII to call for the International Labour Organization to organize a forum on indigenous HIV/AIDS issues, pursuant to health components of Convention 169;
- 4d. UNPFII, UNAIDS, the World Health Organization (WHO), and the Pan-American Health Organization (PAHO) and other partners to engage in a global dialogue on gender inequality, poverty and the structural changes required to the global HIV/AIDS response for indigenous peoples in order to adequately respond to these persistent inequities;
- 4e. IIHAWG and all dialogue participants advocate for funding for indigenous-specific global and/or regional HIV/AIDS prevention campaigns; and,
- 4f. All dialogue participants advocate for better integration of HIV/AIDS issues into indigenous gatherings and better integration of indigenous issues into HIV/AIDS gatherings.

#### RECOMMENDATION 5: BUILD CAPACITY TO INTEGRATE HIV/AIDS AND INDIGENOUS PEOPLES' ISSUES

Participants emphasized the importance of building capacity to integrate HIV/AIDS and indigenous peoples issues. Building capacity requires resource people with the right knowledge, skills and experience, as well as adequate funding. One indigenous chief at the dialogue articulated a pressing need for UN multilateral organizations to encourage national health ministries to sign "peace agreements" with indigenous peoples in their countries, as a means to begin to work collaboratively on health issues that pertain to indigenous communities. He believed that these peace agreements would need to be preceded by a series of discussions between governments and indigenous chiefs to establish trust and open communication.

#### Other recommendations included:

- 5a. Indigenous and HIV/AIDS non-governmental organizations/networks, supported by international bodies such as UNAIDS, should take an active role in ensuring that their countries:
  - Develop a national strategy and workplan for HIV/AIDS and indigenous peoples;
  - Commit to indigenous-specific public health programmes that are culturallyappropriate and culturally-relevant; and
  - Consider training indigenous public health officers to hold salaried positions in national health services.
- 5b. Increase project funding for HIV/AIDS and indigenous peoples through the Global Fund for HIV/AIDS, Tuberculosis and Malaria;
- 5c. Urge HIV/AIDS funding bodies to require inclusion of indigenous communities in development processes as part of application criteria;
- 5d. Advocate for the inclusion of gender and ethnicity in global and regional funding for HIV/AIDS and development;
- 5e. Advocate for increased research funding for HIV/AIDS and indigenous peoples' issues, including research on the effectiveness of the complementary use of traditional and Western medicines;
- 5f. Advocate for financial support to facilitate passing on of cultural traditions, including traditional medicines;
- 5g. Advocate for increased and flexible funding that is more responsive to emerging issues in the HIV/AIDS epidemic (i.e., increasing rates of HIV infection among indigenous peoples, women, youth, people who inject drugs, people in prison); and,
- 5h. Develop regional networks and facilitate South-South and North-South exchanges among indigenous representatives to allow sharing of knowledge, experience and approaches (e.g., establishing indigenous community radio to connect indigenous peoples in Central and South America).

#### **RECOMMENDATION 6:** FACILITATE SHARING OF KNOWLEDGE AND WISE PRACTICES

In areas such as research, surveillance and data collection, there is a growing body of knowledge about modes of transmission of HIV infection and the impact of HIV/AIDS on indigenous communities. There are also a growing number of wise practice examples in areas of HIV/AIDS prevention, testing, treatment, care and support for indigenous peoples, including those specific to men who have sex with men, women, youth and people who inject drugs. However, to date, there has been limited sharing of knowledge and wise practices. Participants recommended putting in place a range of formal and informal mechanisms to facilitate this exchange, including:

- 6a. Health Canada to share information and examples presented at the dialogue through dissemination of the dialogue report;
- 6b. All dialogue participants to share formal policy papers and evaluation reports through the informal networks of dialogue participants;
- 6c. Synthesize and share final reports of the indigenous satellite meetings held in conjunction with recent International AIDS Conferences (i.e. Toronto, Mexico); and,
- 6d. Recognize and support the important role of traditional medicine in the response to HIV/AIDS among indigenous peoples, documenting examples of successful cooperation between Western and traditional medicine to support indigenous PHAs.

## RECOMMENDATION 7: Ensure Meaningful Involvement of Indigenous Peoples in Research, Policy and Programme Development Related to HIV/AIDS

It was expressed that few indigenous peoples have strong representation in national political institutions, nor are they engaged as true partners in the global HIV/AIDS response. Increased participation in policy-making and genuine engagement of indigenous peoples has the potential to significantly reduce the impact of HIV/AIDS on communities. Better cooperation between indigenous peoples, governments and organizations is required, with indigenous peoples supported and engaged in identifying the needs of their communities, finding solutions and implementing policies and programmes.

Participants at the dialogue emphasized the importance of ensuring meaningful involvement of indigenous peoples as well as PHAs, in keeping with the GIPA principle (Greater Involvement of Persons with AIDS). Recommendations included:

- 7a. Include indigenous caucus meetings on the agenda of all fora related to indigenous issues, including those unrelated to HIV/AIDS;
- 7b. Facilitate/ensure for help to build the skills, experience, and knowledge of indigenous peoples and PHAs to participate meaningfully at every stage of research, policy and programme development processes;
- 7c. Expand opportunities for the involvement of indigenous PHAs within national HIV/AIDS movements in order to influence policy and programme development;

- 7d. Develop and distribute guidelines on overcoming barriers to indigenous participation;
- 7e. Seek the participation of youth and elders in dialogues and at policy tables to creatively inform national strategies for HIV/AIDS and indigenous peoples;
- 7f. Use culturally-appropriate and culturally-relevant models/stories to organize and present issues at the regional, national and community levels; and,
- 7g. Encourage international agencies to create opportunities for indigenous peoples to participate in training public health service personnel and academic health researchers.

#### RECOMMENDATION 8: Ensure Accurate Representation of Indigenous Peoples in HIV/AIDS Data

Comprehensive data builds the foundation for all HIV/AIDS research, prevention, treatment, care and support initiatives. However, very few countries have any reliable national surveillance data to indicate the true level of HIV infection among indigenous peoples. The data available is often not disaggregated to support targeted, well-informed policy and programme development. Participant recommendations included:

- 8a. Sensitize national governments about rates of HIV/AIDS among indigenous peoples;
- 8b. Urge UNAIDS to remind countries to recognize indigenous peoples as high risk populations in their national UNGASS reports;
- 8c. Share good examples of sophisticated surveillance methods, data collection tools, analysis and reporting, including monitoring co-infections, and their application to support policy and programme decisions; and
- 8d. Support, enhance and participate in efforts to create internationally comparable indigenous HIV/AIDS indicators, aiming for disaggregated data for population sub-groups (e.g., gender, age, indigenous/ethnic group, route of HIV transmission).

#### **RECOMMENDATION 9:** Promote the Use of an Indigenous Social Determinants of Health Approach

Despite very significant differences in the circumstances of indigenous peoples around the world, there are a number of common indigenous determinants of health. These determinants of health are linked to inequitable social and economic policies and represent the root causes of HIV infection and the impact of HIV/AIDS on indigenous communities. Participants recommended further developing and applying an indigenous-specific social determinants of health approach through the following activities:

- 9a. Expand dialogue and understanding of SDOH to include determinants identified by indigenous peoples such as self-determination, poverty, stigma and discrimination, migration, climate change, inequitable social and economic policies, and racism;
- 9b. Engage key indigenous and non-indigenous health stakeholders (e.g., HIV/AIDS, sexually transmitted and blood borne infections, tuberculosis, diabetes) and non-health sector stakeholders (e.g., poverty, education, housing, environment, etc) in identifying and implementing solutions; and,

9c. Convene a policy dialogue between indigenous community health workers and multiple SDOH sectors to build capacity to apply an indigenous-specific SDOH approach to the HIV/AIDS response.

#### RECOMMENDATION 10: INCREASE YOUTH INVOLVEMENT IN THE HIV RESPONSE

With younger indigenous populations experiencing increasing rates of HIV infection, participants identified the need for immediate action to identify innovative ways to engage youth in the HIV response. These included:

- 10a. Provide support for indigenous youth participation in HIV/AIDS research, policy and programme development, including:
  - Encouraging and utilizing direct youth involvement in forums, education, prevention/treatment activities, etc;
  - Expanding capacity-building initiatives for youth and providing funding to outreach programmes;
  - Providing mentorship and training in research, policy and programme development processes;
  - Creating space in the UNPFII agenda to talk about sexual health issues for indigenous youth; and
  - Providing clear lines of communication and accountability that enable engaged youth to report to other UN Agencies on their activities and recommendations (e.g., UNICEF, UNPFII, UNAIDS).
- 10b. Link HIV/AIDS programmes for indigenous youth to arts and cultural programmes;
- 10c. Adults and tribal leaders in the community should serve as allies to youth, taking the time to respect and listen to their views and to provide advice for youth-led decision-making;
- 10d. Redesign HIV prevention approaches and materials for youth that move away from abstinence-only prevention approaches, which are widely seen to be ineffective;
- 10e. Decriminalize sexuality (e.g., age of consent laws; laws against homosexuality; condom distribution to youth under 16 years of age in some jurisdictions);
- 10f. Ensure resources are allocated for holistic, culturally-relevant treatment and support for indigenous youth PHAs, including options for mobile access for youth in rural, remote locations;
- 10g. Expand research, policy and programme development for youth that address the intergenerational impacts of colonization (e.g., in Canada, residential schools); and,
- 10h. Organize an international indigenous youth and HIV/AIDS forum in conjunction with the 2010 International AIDS Conference and support youth participants to return to their communities and encourage local and tribal governments to join in united action.

#### 6.0 **KEY DISCUSSION THEMES – INDIGENOUS PEOPLES AND HIV/AIDS**

#### 6.1 INDIGENOUS DETERMINANTS OF HEALTH

Participants discussed the importance of developing a better understanding of indigenous determinants of health and their impact on the risk of HIV transmission and on HIV/AIDS prevention, treatment, care and support. These underlying social and economic determinants are the often called the "causes of the causes" of disease. 10 With regards to HIV/AIDS, such determinants can affect access to relevant information and outreach education, access to testing, the willingness to be tested, availability and types of treatment, and care and risks of infection.

#### GLOBAL EFFORTS TO IDENTIFY INDIGENOUS DETERMINANTS OF HEALTH

Presenters shared the results of recent dialogue and research on indigenous determinants of health. In April 2007, an international symposium was organized to support the work of the WHO Commission on the Social Determinants of Health.<sup>11,12</sup> It brought together indigenous peoples, researchers and policy-makers from around the world to discuss the indigenous social determinants of health.

Despite very significant differences in the circumstances of indigenous peoples globally, those who attended the international symposium identified numerous shared issues, key indigenous determinants of health, and their policy implications. These determinants, and others identified by current dialogue participants, include:

- Colonization;
- Self-determination (restoring control to indigenous peoples);
- Detachment from ancestral lands/resource alienation (weakening cultural practices and traditional economy);
- Land degradation and climate change;
- Indigenous poverty and economic inequality; and
- Racism and oppression.

Dialogue participants discussed other social determinants of health that impact indigenous women, including family and sexual violence, social support systems, and living conditions that support healthy behaviours (see Section 6.5). Other determinants specific to particular indigenous groups were shared, e.g., in Canada, the experience of Aboriginal people in residential schools.

Participants discussed the importance of prioritizing indigenous determinants of health where there is the greatest potential for policy change. This effort would support focused action to

<sup>&</sup>lt;sup>10</sup> Public Health Agency of Canada, "What Determines Health?" Available on-line at: http://www.phac-aspc.gc.ca/ph-sp/determinants/index-

eng.php#determinants

11 WHO Commission on the Social Determinants of Health, 2008. Closing the Gap in a Generation: Health Equity through Action on the Social Determinants of Health. Available on-line at: http://www.who.int/social\_determinants/thecommission/finalreport/en/index.html

<sup>&</sup>lt;sup>12</sup> Social determinants and indigenous health: The international experience and its policy implications. A report on specially prepared documents, presentations and reports at the International Symposium on Social Determinants of Indigenous Health, for the WHO Commission on SDOH in April 2007. Available at: http://www.who.int/social\_determinants/resources/indigenous\_health\_adelaide\_report\_07.pdf

better align policies and practices with indigenous values, attitudes and aspirations of indigenous peoples. In the case of HIV/AIDS, this would increase the effectiveness of the indigenous HIV/AIDs response.

Direct interventions at multiple levels are needed to create individual, collective and societal change that will impact social determinants of health. Participants talked about the importance of engaging those working in areas of health outside of HIV/AIDS (e.g., hepatitis C, tuberculosis, diabetes) and those working in non-health sectors, such as poverty, education, housing, justice and employment. Working together can increase understanding of the experience of indigenous communities with HIV/AIDS and can help those involved to identify solutions that address indigenous determinants of health.

#### **POVERTY AND DEVELOPMENT PROCESSES**

Poverty is a determinant of health and an underlying driver of the HIV/AIDS epidemic. While the experience of poverty is not unique to indigenous peoples, there are a disproportionate number of indigenous peoples living in poverty.

Indigenous peoples often feel impoverished as a result of processes that are out of their control and sometimes irreversible. Participants emphasized the devastating impact of colonization on indigenous communities around the world and its implications for HIV transmission, naming colonization as "the cause of the causes of the causes" of disease.<sup>13</sup> When talking about poverty in an indigenous context, it is most relevant to talk about impoverishment processes, which find their roots in colonization, the destruction of indigenous economic and socio-political systems, continuing systemic racism and discrimination, social exclusion, and the non-recognition of indigenous peoples individual and collective rights.

In addition to systemic impoverishment processes, indigenous peoples also experience limitations and barriers caused by lack of income, with many indigenous communities economically disadvantaged compared to other segments of the population. Although indigenous peoples represent 5% of the world's population, they represent 15% of the world's poorest people. Poverty-related indicators for indigenous peoples are linked to their increased vulnerability to HIV/AIDS and a negative impact on social, economic, political, physical and mental well-being.

With the majority of indigenous peoples living in developing countries, international monetary aid and development aid structures have significantly affected their communities. National and international monetary programs that pressure governments to introduce competition in key industries have made it more difficult to maintain traditional ways of life. Indigenous world views, perspectives, experiences and concepts of development have been largely ignored by mainstream development policies and thinking. The loss of land and resources that characterize many indigenous cultures has resulted in a loss of self-sufficiency and contributed to high levels of poverty.

<sup>&</sup>lt;sup>13</sup> Presenter Margo Greenwood credited this quote to Dr. Jeff Redding, Past Scientific Director, Institute of Aboriginal Peoples Health, Canadian Institutes of Health Research.

<sup>&</sup>lt;sup>14</sup> International Work Group for Indigenous Peoples, Goal 1: Eradicate Extreme Hunger and Poverty, http://www.iwgia.org/sw15946.asp

#### HIV/AIDS-RELATED STIGMA AND DISCRIMINATION

Stigma and discrimination are among the key drivers of the HIV/AIDS epidemic, serving as barriers that prevent people from seeking information for prevention, testing, treatment and supports. Living in small or remote communities may present a barrier to accessing anonymous testing for some indigenous peoples. Once diagnosed as HIV positive, there may be fear of disclosure related to cultural taboos or homophobia within indigenous communities. Some indigenous participants shared examples of lateral violence against indigenous PHAs, their families and friends, including exclusion and harassment. The impact of stigma and discrimination on HIV/AIDS data collection and the invisibility of indigenous peoples in the HIV/AIDS response are discussed in Section 6.11.

Indigenous peoples face the double stigma of HIV/AIDS combined with well-documented historical and persistent forms of institutional racism, stigma and discrimination. Participants shared examples of institutional racism where indigenous peoples are not afforded equal rights by state governments or the health system. For example, in New Zealand in 2009, the Crown has referred to HIV as a white gay man's disease despite increasing rates of infection among Māori peoples, including women and children.<sup>15</sup>

In Latin American countries, indigenous participants shared experiences of being excluded by national governments from national HIV/AIDS strategies and policy and programme development processes. Dialogue participants alleged that state governments have not allocated adequate funding to support HIV prevention, testing, treatment and supports for indigenous peoples, and have been unwilling to guarantee the rights of indigenous peoples to accessible, culturally-appropriate and culturally-relevant health services.

Participants called for actions to raise awareness of stigma and discrimination as an indigenous determinant of health, to eliminate racism and homophobia within indigenous communities and broader society, and to shift away from health and development policies and practices that systematically discriminate against indigenous peoples.

#### 6.2 MODES OF TRANSMISSION

Very few countries have any reliable national surveillance data to indicate the true level of HIV infection among indigenous peoples. Australia, Canada and the United States produce the most surveillance data on HIV/AIDS among indigenous peoples. The limitations of HIV/AIDS surveillance and data collection, and the implications for research, policy and programme development are included in Section 6.11.

As part of the dialogue, country-specific presentations were given to share what is known about transmission of HIV infection among indigenous peoples in Canada, Australia, New Zealand and Chile. All presentations provided HIV/AIDS data in the context of key indigenous social determinants of health such as poverty, social exclusion and the experience of colonization.

According to available data, transmission follows a different pattern for indigenous peoples

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<sup>&</sup>lt;sup>15</sup> From presentation by Apihaka Mack.

than it does for the general population. There is also a different pattern of transmission for indigenous men and women. Modes of transmission vary between countries in the North and South, and within these regions.

#### HIGHER PROPORTION OF NEW HIV DIAGNOSES AMONG INDIGENOUS PEOPLES

According to available epidemiological data, the HIV epidemic among indigenous peoples is showing no signs of slowing. In Canada, Australia, New Zealand, and the United States, indigenous peoples are making up a growing percentage of positive HIV test reports and reported AIDS cases.<sup>16</sup> Although data are limited in developing countries, participants from Chile, Brazil and Guatemala anecdotally identified similar trends in their communities.

#### HIGH RATES OF HIV TRANSMISSION BY INJECTION DRUG USE IN DEVELOPED COUNTRIES

Injection drug use (IDU) is the most common mode of HIV transmission for indigenous peoples in some developed countries (e.g., Canada and the United States), with a higher proportion of indigenous peoples infected by IDU than the general population. For example, in Australia, there has been a higher proportion of IDU transmission among the Aboriginal and Torres Strait Islander population (22%) than the non-indigenous population (3%). Similarly, the proportion of new HIV infections in 2005 due to IDU among Aboriginal persons in Canada (63%) is much higher than among the general population (16%).<sup>17</sup> In 2003, Canadian investigators concluded that Aboriginal people who inject drugs were becoming HIV positive at twice the rate of non-Aboriginal people who inject drugs.<sup>18</sup>

In Canada, the rate of HIV transmission through IDU among indigenous women is almost twice the rate of heterosexual transmission. The high stigmatization of IDU may limit access to services and marginalize indigenous peoples with drug dependence from seeking support and care.

#### HIV Transmission Amongst Men Who Have Sex With Men (MSM) And The Experience Of Homophobia

In some developed countries, men having sex with men is reported as the most common mode of transmission among indigenous peoples. However, in other developed countries, and in developing countries, reported indigenous HIV cases attributed to MSM are less common than reported cases through heterosexual transmission.<sup>19</sup>

Dialogue participants discussed how the presence of homophobia in indigenous communities

<sup>&</sup>lt;sup>16</sup> In Canada, new HIV infections among Aboriginal peoples accounted for approximately 9% of the total new infections in 2005, with an overall infection rate about 2.8 times higher than among the general population; Aboriginal persons accounted for 24.9% of all HIV positive test results between 2004 and 2008. In the United States, American Indians/Alaskan Natives are the population groups that now rank third in rates of HIV Incidence (14.6/100,000 HIV diagnoses). In Chile, it was stated that data is unavailable, although indigenous communities living in remote, isolated regions have experienced HIV infection among their people; in some cases, HIV infection has been linked to practices of sexual initiation of young men.

<sup>&</sup>lt;sup>17</sup> Original stats (before corrections) are from slide 14, presentation by Chris Archibald

<sup>&</sup>lt;sup>18</sup> From slide 14, presentation by Chris Archibald

<sup>&</sup>lt;sup>19</sup> In Australia, the most frequently reported route of transmission was sexual contact between men in both the non-indigenous population (67%) and in the Aboriginal and Torres Islander populations (54%); heterosexual transmission accounted for 23% of all HIV infections, both in the Aboriginal and Torres Islander population and non-indigenous population. In Canada, heterosexual transmission among Aboriginals accounts for 28.3% of all HIV infections, with MSM accounting for 6.8% and MSM/IDU for 3.6%.

In New Zealand, there are 15 – 20 new infections on average per year among Māori men who have sex with men, with a rate of 1.3 Māori MSM for every 1.0 MSM of European origin infected. In Brazil, 60.7% of reported indigenous HIV cases are through heterosexual transmission, 33.4% through MSM and 6.7% through IDU; more men are affected than women, with a ratio of 1.6 men infected for every woman

creates an environment of isolation and exclusion for indigenous gay men and MSM. The stigma within indigenous communities compounds the experience of stigma in broader society. It may also skew data collection, with men choosing to identify as heterosexual rather than face the stigma of disclosing they have been sexually active with another man.

Participants noted that some countries are further ahead in combating homophobia than others. For example, in some Latin American countries there are strong cultures of homophobia and fear, with no laws in place to ensure the legal rights of MSM and transgendered people. This may be a barrier to indigenous MSM seeking HIV-related information and health services. Fighting this stigma, both within and outside indigenous communities, needs to be considered in the HIV/AIDS response.

Participants also noted that there is recent epidemiologic evidence that suggests that men having sex with men may be a significant driver of the HIV/AIDS epidemic in some developing countries.<sup>20</sup> They also emphasized the value and importance of using language that includes the wide diversity of gender identities and that reflects the varied cultural understandings of sexuality. Section 6.4 explores the theme of Gender Identities and Sexual Diversity.

#### HIGH RATES OF HIV TRANSMISSION AMONG INDIGENOUS WOMEN

HIV/AIDS has a significant impact on indigenous women, with women making up a significant proportion of the epidemic in many indigenous communities.<sup>21</sup> In some developed countries, IDU is a frequent mode of transmission among indigenous women. This is in contrast to developing countries, such as Papua New Guinea, where heterosexual transmission is the most frequent route of infection.

There is a different pattern of HIV transmission for indigenous men and women. Research indicates that this difference is associated with relations of power. Section 6.5 presents the impact of HIV/AIDS on indigenous women and implications for policy and programme development.

#### Young Age of HIV Infection

Indigenous peoples in some countries are experiencing a growth in population, with a high proportion of people under 25 years of age. For example, there is an expected 40% increase in the Aboriginal and Torres Strait Islander population of Australia over the next fifteen years.

At the same time, indigenous peoples are being infected with HIV at a younger age compared to the general population. In Canada, 27.7% of Aboriginal HIV diagnoses are among the 20-29 age cohort compared to 19.5% in the non-Aboriginal population.<sup>22</sup> Data is limited and likely masks

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<sup>&</sup>lt;sup>20</sup> Dialogue participants indicated that data on MSM transmission as a driver in developing countries was presented at the 23<sup>rd</sup> International World AIDS Conference in Mexico City. Those who had attended the relevant conference sessions offered to forward the information to Health Canada to be included with the list of reports and resources in this dialogue session.

<sup>&</sup>lt;sup>21</sup> In Canada, Aboriginal women accounted for 48.1% of all HIV infections compared to 20.7% of infections among non-Aboriginal women between 1998 and 2006. In New Zealand in 2008, there was a 48% increase of the number of women diagnosed with HIV infection, with 2.8 Māori women infected with HIV for every woman of European origin infected; 40.6% of women diagnosed with AIDS or receiving a late-tested diagnosis are Māori. In Australia, a higher proportion of HIV infections were among women (26.9% among Aboriginal and Torres Strait Islander cases vs. 11.6% for non-Indigenous cases). In the United States, the rate of HIV diagnosis for American Indians/Alaska Natives (AI/AN) females (4.6) nearly double in rate of white female (2.9)

<sup>&</sup>lt;sup>22</sup> From slide 18, presentation by Chris Archibald

regional differences across the country; however, according to non-scientific data based on the experience of Aboriginal communities in central Canada there may be an emerging heterosexual, youth epidemic.<sup>23</sup>

This trend underscores the importance of ensuring indigenous youth have access to information about sexual health, HIV prevention, and injection drug use. Section 6.6 presents the impact of HIV/AIDS on indigenous youth and implications for policy and programme development.

#### 6.3 POLITICAL GEOGRAPHY

The places and conditions in which people live play a significant role in their health and well-being. This includes a range of geographic (e.g., urban/rural, mobility, migration) and political factors (e.g., government policies, sovereignty, relocation/dislocation, resource use). Taken together, these factors are termed "political geography". Political geography impacts the barriers to HIV prevention, treatment, care, and support experienced by indigenous peoples.

Dialogue participants discussed how aspects of the political geography in their regions have impacted their vulnerability to HIV infection and the ability of their communities to respond to the epidemic.

#### LIVING IN RURAL, REMOTE AREAS

Many indigenous peoples live in rural areas that are remote and isolated from the larger population. Early in the HIV/AIDS epidemic, this geographic isolation may have served as protection from transmission of HIV to the community. However, once HIV infection is present it may spread quickly through a community due to this same isolation. Lack of knowledge and awareness of HIV increases the vulnerability of these communities to infection.

People living with HIV who live in urban centres may return to their rural communities when they are sick, and leave their orphaned children there when they die. In many places, traditional coping strategies based on the extended family and stable rural communities are strained from the burden of sickness and care. This can undermine agricultural productivity and the ability of households to meet their basic needs. Scarce resources make it difficult for communities to cope with the impact of HIV/AIDS.

#### LAND USE, ECONOMIC DEVELOPMENT POLICIES AND RESOURCE EXTRACTION

In some regions, government policies have forced the migration and displacement of indigenous peoples from their traditional territories. This practice has had a large impact on HIV transmission among indigenous peoples. Although there are often laws that protect the rights and culture of indigenous peoples, political leaders do not always ensure these rights.

For example, more than 20,000 indigenous peoples from different ethnic groups in Brazil were forced to live together in 3,400 hectares because their land rights were not guaranteed. Many health and social problems developed and there has been limited access to state health care. In

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 $<sup>^{23}</sup>$  Comment by Chris Archibald in plenary during the question/answer session, Day 1

other cases, such as in Colombia and Brazil, indigenous peoples have been forced from their homes with fire and have had to migrate to the poverty belts on the outskirts of large urban centres. Under these circumstances, many women have turned to sex work to support their families and have thereby been placed at high risk of HIV infection.

Similarly, government policies have disrupted traditional economies, with many men forced to leave their traditional territories to seek work in urban centres. They find themselves living in unfamiliar environments for long periods of time, away from their wives, children and cultural traditions. They may become infected with HIV, transmitting the infection to women in their communities upon their return home.

In some cases, government policies have permitted corporations to penetrate traditional territories for the purposes of resource extraction. This creates a new local economy and source of employment for migrant workers. Indigenous women in contact with these migrant workers are highly vulnerable to HIV/AIDS, having little knowledge of the background of the migrant workers or awareness of the risk of infection. There are anecdotal reports of women, children and youth dying in indigenous communities without any knowledge that the cause is HIV/AIDS. This lived experience serves as valuable information to inform policy and programme development in the absence of other available data. Further research and surveillance in these areas will allow a more accurate assessment and ensure that, where HIV is present, those affected are not invisible in the statistics and the HIV response.

In the North American context, economic development policies have led to the expansion of the gaming industry on tribal lands. There are questions that have been raised about whether HIV risk behaviours of the local population are increasing as a result of new gambling establishments (e.g., alcohol or substance use, depression, risky sexual behavior, etc.). Similarly, in Australia, increased injection drug use has been observed in areas where indigenous peoples receive royalties from mining/land use.

#### **DIVERSITY AS A CHALLENGE TO THE HIV RESPONSE**

Political geography also takes into consideration the changing demographics of the population, such as age, language, number and location of indigenous communities and tribal lands. Diversity of languages and cultures and the physical distance between small, remote communities present challenges for HIV/AIDS prevention, testing, treatment and support. For example, in Brazil alone there are over 210 indigenous ethnic groups, speaking 170 different languages, living in 3,751 dispersed communities and 430 different municipalities.

#### **INEQUITABLE RESOURCE ALLOCATION POLICIES**

Participants discussed how inequitable regional and national development policies impact on indigenous communities. For example, in Brazil, the majority of the indigenous lands are concentrated in the Northwest Amazonian region (98%), where 60% of the indigenous peoples live, representing 7% of the regional population. In contrast, the Southeast region includes 40% of the total population, but only 3% of indigenous peoples. Because regional funding, public policy and investments are made based on where people live (i.e., on a per capita basis), fewer resources are allocated to the Northwest region, where there is a concentration of indigenous peoples. This inequitable resource allocation policy places indigenous peoples in a

situation of social and economic vulnerability.

#### MOBILITY AND ACCESS TO SERVICES: URBAN VERSUS RURAL

In some countries, there are high levels of mobility among indigenous peoples. There are a variety of underlying reasons for varying rates of mobility, depending on the regional context, often related to limited educational/employment opportunities, disruption of traditional economies and the desire to seek a safer environment away from the social problems that may exist at home or in the community. Indigenous youth, a growing segment of the indigenous population, tend to be especially mobile.<sup>24</sup>

Government policies aimed at increasing support to PHAs can unintentionally introduce unequal access to health services for some population groups. For example, in the US the Government developed the Ryan White Care Act (RWCA) to support treatment and care of all PHAs. In terms of American Indians and Alaska Natives, this has led to the development of specialized HIV/AIDS services concentrated in urban locations. PHAs may move to these urban locations to access services, leaving their tribal lands, support infrastructure and culture/traditional ties behind. In contrast, those that choose to remain in their home communities may find it more difficult to follow recommended treatment without the direct HIV/AIDS specialized program support.

In Canada, there is the concept of urban reserves, with a large Aboriginal population living permanently or transiently in urban centres. This mobile population can experience a lack of access to services that are culturally-relevant to their particular Nation. (e.g., there may be another First Nations teaching that is predominant, or the services may be focused on First Nations people but not on Métis or Inuit needs). In Australia, there is a combination of local, indigenous-controlled services and those provided by AIDS councils in the larger urban centres. This provides the mobile population with services in both their home community and the city.

#### LATE DIAGNOSIS/RATES OF SURVIVAL AFTER AIDS DIAGNOSIS

Participants discussed the lower rates of survival of indigenous peoples after HIV diagnosis when compared with non-indigenous survival rates. For example, US data indicate there is a similar time period from HIV diagnosis to developing AIDS for all races/ethnicities, including American Indians/Alaska Natives (AI/AN). However, American Indians/Alaska Natives experience the shortest length of time from AIDS diagnosis to death. In New Zealand, Māori present later with HIV infection than the non-Māori population, accounting for 40.6% of AIDS or late tested diagnoses. Some research indicates that this lower rate of survival of American Indians/Alaska Natives after diagnosis could be explained through factors of political geography and health disparities linked to indigenous determinants of health.

#### 6.4 GENDER IDENTITIES AND SEXUAL DIVERSITY

Indigenous presenters shared their diverse cultural practices and understandings of gender identity and sexual diversity. Participants discussed the stigma and discrimination that exists

<sup>&</sup>lt;sup>24</sup> For example, in the United States, urban Native Indians exhibit higher rates of mobility than non-Natives, moving both within the same county and from one county to a different county.

in many indigenous communities against gay, lesbian, bisexual, transgendered and two-spirited persons. They discussed the origins of this discrimination and the importance of bringing about a shift to greater acceptance and understanding in order to carry out an effective HIV response in indigenous communities.

#### USING INCLUSIVE LANGUAGE AND ENSURING CULTURAL RELEVANCE

Participants felt strongly about the use of inclusive language in analysis, reports and discussions about the HIV response. It is necessary to acknowledge and talk about sexual diversity using language that names people of all sexual and gender identities, including gay, lesbian, bisexual, transgendered, and two-spirited. The use of inclusive language not only combats stigma, but also ensures that all peoples are visible and have equitable access to HIV prevention, testing, treatment and support services.

#### TRADITIONAL UNDERSTANDINGS OF HEALTHY SEXUALITY AND THE IMPACT OF COLONIZATION

Indigenous cultures have different understandings of sexuality. These understandings are often rooted in holistic world views where sexuality is a part of creation, connected to their ancestry and cultural traditions, the cycle of life, and their natural environment.

However, colonization has had a significant impact on sexuality among indigenous peoples. Colonization brought strict moral beliefs and attitudes imposed by Christianity and the eradication of traditional practices. For example, in both North America and New Zealand, contact with foreign cultures led to suppression of traditional views, respect for sexual expression and the special gifts that sexuality brings. Indigenous communities are making efforts to reclaim their traditional understandings of healthy sexuality. Participants viewed this as an important element of the indigenous HIV response. Wise practices in this area are presented in Section 6.12.

#### SEXUAL DIVERSITY IN TRADITIONAL INDIGENOUS CULTURES

In some indigenous cultures, sexual diversity was historically accepted and celebrated. Māori and Aboriginal-Canadian presenters shared ancestral stories and images illustrating how sexual diversity and healthy sexuality are part of their traditional cultures. For example, Māori art work, oral histories, written accounts and archival materials illustrate that sexuality was enjoyed in all its diversity, with partners of either sex, without community members being condemned or vilified.

Some indigenous dialogue participants talked about how in the past their traditional cultures had very open views and wide acceptance of sexual practices and orientation. Traditional languages have names inclusive of people with diverse gender identities. For example, some Aboriginal peoples in North America use the term two-spirited to describe people who have both masculine and feminine spirits living in the same body.

<sup>&</sup>lt;sup>25</sup> For example, the Aboriginal peoples of North America viewed sex as a very normal expression of a person's emotional, spiritual, mental and physical being. Sexuality was perceived as much more than just a means of reproduction; it was also seen as a special gift from the Creator that was a means of sharing themselves with their partner(s). Traditional Aboriginal societies had some way of recognizing the passage from childhood to adulthood. Sexual initiation of young men was noted also as a traditional practice among some indigenous peoples in Chile.

<sup>&</sup>lt;sup>26</sup> Languages of several First Nations have names for two-spirit, e.g., Nadeleehe (Navaho), Wintke (Lakota), Warharmi (Kamia), Ogokwe (Ojibiwe). There is a Māori word, "takatapui" which means "intimate companion of the same sex".

The discussion of gender and sexual identities is new for some indigenous peoples, for example, in Guatemalan and Mayan cultures. Participants from this region talked about how it could be helpful for their people to hear about the experiences and understandings of those living in other regions. This support could open up discussions, reduce stigma, and broaden the HIV response in Guatemala and other Latin American countries.

#### REGIONAL DIFFERENCES IN MOVING FORWARD SEXUAL RIGHTS

Participants agreed that discussions about HIV/AIDS need to be inclusive of the rights of all peoples, including gay, lesbian, bisexual and transgendered people. However, they also discussed the different cultural realities in which people live and the importance of being respectful of those realities. A global framework for action on HIV /AIDS and indigenous peoples will need to support regional flexibility in approaches, while providing a platform of mutual support in areas of common priority.

#### 6.5 INDIGENOUS WOMEN AND HIV/AIDS

Indigenous women often account for a large proportion of HIV/AIDS cases when compared to non-indigenous women. However, it is important to put the data in context to avoid increasing stigma or pathologizing indigenous women. For example, in Canada, Aboriginal women make up 48% of all reported Aboriginal HIV positive tests, and 12% of total reported HIV positive tests where ethnicity data was collected; however this represents only 0.1% of all Aboriginal women.<sup>27</sup>

#### RACIST SEXISM AND VIOLENCE AGAINST INDIGENOUS WOMEN AND GIRLS

Presenters discussed studies in Canada and Papua New Guinea about indigenous women's experience of violence and how this violence increases vulnerability to HIV infection. Participants affirmed that women and girls face widespread racialized, sexualized violence.

Violence and trauma experienced by indigenous women has its roots in colonization. Indigenous women experienced conflict, rape as a weapon of war, the breakdown of healthy family structures and women's traditional cultural role and authority. Today, violence against indigenous women continues through rape, intimidation, verbal abuse, targeted violence against indigenous sex trade workers, sexual abuse as children and witnessing physical violence against mothers, sisters and other relatives. All of these acts perpetuate feelings of powerlessness which can increase vulnerability to HIV infection.

In the Canadian context, the term "racist sexism" was used to describe social scripts depicting Aboriginal women as inferior, which perpetuates racially motivated exploitation and violence. Interviews with Aboriginal women in Canada led to identifying racist sexism as the core from which a web of other circumstances may lead indigenous women to be exposed to HIV. These circumstances included lower education and employment, sexual violence, poverty, stress/anxiety/post-traumatic stress disorder, addiction as coping, punitive social services, unhealthy relationships and/or sex work. As part of their daily survival strategies, some

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<sup>&</sup>lt;sup>27</sup> From slides 3 and 4, presentation by Charlotte Reading

Aboriginal women share needles, have unprotected sex when high or trade unsafe sex for money, drugs or shelter.<sup>28</sup>

Violence against women is also one of the main drivers of the HIV epidemic in Papua New Guinea (PNG), where two out of three women have experienced forced sex. PNG has the highest rate of HIV infection in Asia-Pacific, with heterosexual transmission being the most common source of infection. In 2008, HIV infection rates among women were almost double the rate of infection among men. Five times as many young PNG women were diagnosed than young PNG men.

#### GIVING VOICE TO INDIGENOUS WOMEN AND GIRLS

Participants talked about the importance of empowering indigenous women to speak about their own experiences with HIV/AIDS. There are some projects in place, such as Hearing Our Stories in the United States, aimed at providing women who experienced violence to share their stories, helping to break down barriers through HIV education. This type of project could potentially serve as a model for other countries.

#### INCLUSION OF MEN AND BOYS/ENGAGING INDIGENOUS COMMUNITIES

Participants talked about using approaches that involve indigenous men and boys to shift negative perceptions of gender roles and to prevent violence against women in their communities. There are examples of programs in North America focused on re-education about the traditional roles of men and women and about decolonization, such as the Yankton Sioux Men's Re-Education Project, in South Dakota in the United States.

Participants were sensitive to the portrayal of indigenous men as perpetrators of violence. When talking about indigenous heterosexual men committing violence against indigenous women, it is important to realize that those men themselves have been victims of the colonial destruction of a much more equitable, respectful, culture-based relationship between men and women. Re-education of young men refers to helping them gain knowledge about what it means to be a man from an indigenous perspective.

#### SAFER WORKING CONDITIONS FOR SEX TRADE WORKERS

A presenter from Maggie's, an advocacy organization run by sex workers in Toronto, Canada, talked about the benefits of decriminalizing the sex trade to break the cycle that can lead to HIV infection. This work is stigmatized both within law in many countries as well as society in general. This stigmatization leads to a lack of support and education for those who work in the sex trade and increased risk of unsafe drug use, unsafe sex, low self esteem and bad self image for workers.

This often leads to sex workers becoming subject to violence both within their work environment as well as in their communities. Decriminalization removes the social stigma attached to sex work and recognizes it as legitimate work. With decriminalization, sex workers can work freely without the menace of criminal charges, and police harassment.

<sup>&</sup>lt;sup>28</sup> Prentice, Tracey. HIV/AIDS and Aboriginal Women, Children and Families: A Position Statement. Ottawa: Canadian Aboriginal AIDS Network, March 2004.

#### 6.6 INDIGENOUS YOUTH AND HIV/AIDS

In general, youth are vulnerable to HIV infection as a result of many factors, including risky sexual behaviour, substance use (including IDU) and perceptions that HIV is not a threat to them. Indigenous youth have additional risks, related to:

- Early age of sexual activity:
- The presence of high rates of sexually transmitted infections (STIs) that can increase the risk of contracting HIV<sup>29</sup>, and
- The impact of colonization.

Participants discussed the implications of a growing, younger indigenous population faced with increasing rates of HIV infection. Youth and older participants exchanged ideas to build a better understanding of the issues and approaches to HIV/AIDS prevention, treatment, care, and support for indigenous youth.

#### A Young, Growing Generation and Increasing Rates of HIV Infection

Many indigenous populations are experiencing a growth in population, with a higher proportion of children and youth in their communities than in the past.<sup>30</sup> At the same time as the younger generation is growing, rates of HIV infection among indigenous youth are increasing. In Canada, almost one in four youth who tests HIV positive is Aboriginal. Aboriginal youth represented 26.5% of new HIV infections among Aboriginal people, compared to 19% of non-Aboriginal youth infections.<sup>31,32</sup>.

In some countries, data show a shift in the pattern of HIV transmission among indigenous youth away from heterosexual transmission toward IDU and MSM. For example, Canadian data show that IDU and MSM accounted for one third of HIV infections, with heterosexual exposure at 14.5% in those under 30 years.<sup>33</sup> This differed from those in older age groups (i.e. 40 years and older) in which heterosexual exposure accounted for the larger proportion of infections.

#### **ADULT SUPPORT FOR YOUTH**

Youth presenters from North America shared their views on how adults can best support Aboriginal youth working in organizations and in community. They encouraged adult participants to be allies of youth while supporting youth in taking on leadership roles and helping them to secure funding for projects they would like to do.

Within an organization this could mean taking on the role of advisor while also ensuring that the youth have the power to make decisions and to run programs. On a policy level, adults can help share analysis and tactics with youth so that they understand how the system works. In

<sup>&</sup>lt;sup>29</sup> One study estimated a 2-5 fold increase in the rate of acquiring HIV infection when syphilis is present. The rate of diagnosis for syphilis of remote Australia and Torres Strait Islander populations was found to be 81 times the non-indigenous rate.

<sup>&</sup>lt;sup>0</sup> In Guatemala, 60-70% of the population are indigenous peoples, with those under 25 years accounting for 45% of the indigenous population. In Brazil in 2000, 43.7% of the indigenous population were under the age of 15 years.

<sup>&</sup>lt;sup>31</sup> From Day 2 presentation by Jessica Ye (from recorded notes – unable to access Power Point to verify primary source)

<sup>&</sup>lt;sup>32</sup> See Section 6.2 – Modes of Transmission

<sup>&</sup>lt;sup>33</sup> From plenary notes, but unable to track the speaker who gave this stat – need to replace with referenced stats, as suggested

organizations and in community it is helpful when adults take the time to talk with youth, to listen to their ideas, and to answer their questions. These approaches can lay the foundation for positive organizational change.

Tribal leaders should make time to talk to youth about issues in the community and about youth's ideas and solutions. This can create a sense of connection between youth, tribal leaders and elders, and a potential opportunity to share traditional knowledge and teachings. Older youth can shift to an advisory/ally role as they mature, serving as mentors in youth-led organizations. Organizations and communities can support this kind of transition, and help older youth to take on new roles and to pursue their career goals.

#### **ENSURING SURVIVAL OF INDIGENOUS LANGUAGE, CULTURE AND TRADITIONS**

Participants discussed the central role of traditional knowledge as well as youth culture in approaches to HIV/AIDS prevention and support programs. It is important for youth to be able to talk about and understand the impact of colonization on themselves, their families and communities. Building in traditional knowledge about gender roles and healthy sexuality can strengthen cultural identity and build the capacity of youth to protect themselves from HIV infection.

For example, indigenous peoples in Chile are experiencing "a generation interrupted" through the loss of a generation of youth who will not have children. There is great concern about how language, culture and traditions will be passed along to the next generation. Support is needed from international bodies, national governments and civil society. One participant indicated that, otherwise, the introduction of HIV infection into their communities will go down in history as a form of genocide toward this centuries old indigenous population.

#### INDIGENOUS YOUTH-TO-YOUTH PEER EDUCATION AND SUPPORT

Among indigenous peoples, sex education traditionally occurred at home or in the community. This is no longer the case in some indigenous communities, where the home or community can, in fact, be the most difficult places for indigenous youth to have conversations about sex or healthy sexuality. More openness with indigenous youth about healthy sexuality, drug use and the impact of colonization has the potential to improve the effectiveness of HIV/AIDS prevention efforts.

Participants discussed the strengths of youth-to-youth peer programme approaches for HIV/AIDS prevention and support. Supporting youth to lead and develop programmes can help to ensure their relevance. Youth will receive clearer, simpler messages that make sense to them, and will feel more comfortable sharing their concerns openly with other youth.

#### **HIV/AIDS TREATMENT AND SUPPORT FOR YOUTH**

For the most part, HIV/AIDS funding for youth has been channelled into prevention and not into treatment and support. Participants discussed how youth do not typically feel welcome or comfortable in established AIDS Service Organizations (ASOs), which often do not meet their unique needs. Holistic HIV/AIDS treatment goes far beyond providing and monitoring medication, and should also include helping youth cope with all aspects of their life at this

important transition period. With the increased rate of HIV infection among youth, funders need to be educated and encouraged to allocate funds to HIV/AIDS treatment and support programs for all youth, particularly indigenous youth.

Youth participants also talked about the stigma and discrimination against gay, lesbian, bisexual, transgender, and two-spirited indigenous youth from both within indigenous communities and outside. They may experience lack of acceptance from peers or their families, hatred and harassment, and are often treated as outsiders within their community. As a result of this tremendous pressure and isolation, they may turn to alcohol, drugs or suicide. Peer outreach programs are now in place in some areas to provide support to gay, lesbian, bisexual, transgender and two-spirited youth, as well as HIV prevention information and a safe, confidential HIV testing service.

#### YOUTH INVOLVEMENT IN RESEARCH AND POLICY DEVELOPMENT

Over the past ten years, there have been efforts made to increase youth participation in the public policy process. Initiatives have been undertaken through the UN and other international bodies and championed by non-governmental organizations around the globe to promote youth participation in governmental processes. 34

In the case of Latin American countries, the responsibility for ensuring youth participation has generally been assumed by the state, but with varied success.<sup>35</sup> The North American context is different, with indigenous youth representing a much smaller proportion of the total population. <sup>36</sup> There is much room for better engaging indigenous youth at the policy level, but it requires investment of resources to build capacity for participation.

Youth involvement in community-based research can strengthen HIV/AIDS policy-making and programme development processes. Involvement of youth as health researchers through community-based research in sexual and reproductive health will allow them to reclaim traditional knowledge, take ownership over their traditional culture, and build their capacity to take action to prevent HIV/AIDS in their communities.

#### 6.7 TRADITIONAL AND WESTERN MEDICINE

Participants discussed the sacred nature of traditional medicines and the importance of maintaining indigenous autonomy and choice of medicines. This encompasses indigenous peoples' right to health and to services that respect their language, culture and traditional healing practices. They shared practical examples of cooperation between traditional and Western medicines and talked about efforts to develop policies that support the use of

<sup>34</sup> The UNPFII has an indigenous youth caucus in place. The caucus has a specific place on the agenda for participating in sessions of the UNPFII. The youth caucus is well organized and has been active in expressing the concerns of indigenous men and women, looking at intergenerational issues between youth, adults and seniors. Although youth have a visible place at the UNPFII, there was some frustration expressed at their ability to influence the broader agenda. For example, the youth forum of the UNPFII has had a difficult time raising sexual health and HIV/AIDS on the agenda.

<sup>&</sup>lt;sup>35</sup> In Bolivia, a new planning system is being organized with strong participation from youth, bringing in the youth concepts of well-being for both urban and rural indigenous peoples. In Ecuador, youth have recently participated in the process of drawing up the new constitution. In Columbia, indigenous youth are well-organized, and seen in a leadership role. In Guatemala, there is a youth congress connection to the national legislature; however, the current structure limits the ability of youth to make real change at the public policy level.

<sup>36</sup> The Canadian Aboriginal AIDS Network is taking steps to ensure that Aboriginal voices will be heard on a national level through the creation of a National HIV/AIDS Aboriginal Youth Council.

traditional medicines and healing practices.

#### RESPECT FOR SACRED NATURE OF TRADITIONAL MEDICINES

Indigenous peoples most often have a holistic view of health and well-being that includes emotional, spiritual, mental and physical health. Traditional healing uses ancestral practices that were in place before Western medicine, including herbal, mineral and animal remedies, participation in ceremonies, one-to-one consultation with elders and others, song, and other cultural practices.

While the specific practices of indigenous peoples vary, there is a common belief and respect for the sacredness of traditional medicines and the wisdom of healers in their communities. The use of traditional medicines is passed down by elders to preserve ancestry, sacredness and the integrity of cultural traditions.<sup>37,38</sup>

#### PROTECTION OF TRADITIONAL MEDICINES FROM APPROPRIATION AND COMMERCIALIZATION

Participants talked about the importance of indigenous peoples maintaining control and autonomy over their traditional knowledge and medicines. In the past, pharmaceutical companies have used traditional knowledge and medicines for their own benefit, with no respect of compensation for indigenous peoples. They expressed concern that research and use of traditional medicines will not be valued or respected. Policies should be in place to ensure that research or use of traditional medicines is valued and respected, and to protect their misuse and appropriation. Policies are also needed to protect the natural environment where indigenous peoples find the trees, herbs, plants, animals and minerals that are used in traditional medicines.

#### **ENSURING INDIGENOUS PEOPLES AUTONOMY AND CHOICE OF MEDICINES**

It is essential that differences in understanding of health, disease, and healing are respected when working with indigenous peoples to develop policies and programmes.<sup>39</sup> Participants discussed the difference between the terms culturally-appropriate and culturally-relevant, defining culturally-appropriate as ensuring services such as translation and interpretation that might be appreciated by the indigenous people. However, participants felt that the term culturally-relevant goes farther than this definition to include a choice of medicines and autonomy in decisions about health. National governments can work to provide culturally-appropriate services, but it is indigenous peoples themselves that must work to create culturally-relevant services, ensuring they are respected and supported within public policies. National governments and indigenous peoples can collaborate to find the policies that are both culturally-appropriate and culturally-relevant.

There are specific examples of government policies aimed at providing culturally-appropriate

<sup>&</sup>lt;sup>37</sup> In some cases, there has been pressure for traditional healers to receive Western training so they can be paid; however, this may not be in keeping with the cultural role of the healer. For example, in Mayan culture, the role of the midwife grandmother is not a paid health practitioner, but an elder in the community who has ancestral knowledge and who provides connection to mother earth and her healing nowers.

powers.

38 In Canada, there has been some loss of traditional indigenous knowledge of traditional medicines. However, there are examples of elders agreeing to instruct community members on making traditional medicines for PHAs.

<sup>&</sup>lt;sup>39</sup> Some indigenous tribes have chosen not to work with government or Western healers in order to preserve the sacredness and the power of their traditional medicines. They have had past experiences where Western approaches have been imposed on them.

and culturally-relevant services. For example, in Brazil through FUNASA, agreements have been negotiated with the hospitals to provide interpreters that understand the language and the culture of the indigenous peoples, including the ceremonies and the medicines. However, participants discussed the need for broader national policy frameworks that ensure the legal rights of indigenous peoples to culturally-appropriate and culturally-relevant health services.

#### **COOPERATION BETWEEN TRADITIONAL AND WESTERN MEDICINE**

There are a growing number of examples of Western practitioners and traditional practitioners meeting to build understanding and to identify ways to work together. There are also practical examples of Western healing and traditional healing practices being used together to benefit indigenous PHAs.

**US Experience** - The Indian Health Service has hosted a number of summits that have brought together traditional healers and Western doctors. Participants discussed how to work toward mutual agreements where both traditional and Western medicines are provided to support indigenous PHAs.

**Canadian Experience** - In Canada, there are hundreds of Aboriginal peoples who access HIV/AIDS services and there are good examples of Western and traditional medicine working together. For example, one hospital in Toronto has been supportive of elders performing ceremonies for indigenous PHAs approaching the end of life. This activity has been supported and respected by the health professionals providing care.

**Guatemalan Experience** - Mayan people are working with the Ministry of Health and a team of technical advisors to provide culturally-appropriate health services. This includes building links between Western-trained doctors and grandmothers and midwives who use traditional health practices and a Mayan vision of health.

**Chilean Experience** - Indigenous leaders have been working to increase their knowledge, to learn how to use traditional medicines for treatment, and to advocate for government supports for prevention, testing, treatment and support.

#### **NATIONAL POLICIES TO SUPPORT TRADITIONAL KNOWLEDGE AND MEDICINES**

Participants discussed opportunities and challenges in working with state governments to support the use of traditional medicines in general, and in HIV/AIDS treatment and support in particular. Policy frameworks need to consider indigenous peoples' right to health and to equitable access to culturally-relevant HIV/AIDS services in their own language.

At this time, Western medicine is the dominant form of health services available to Aboriginal peoples in Canada.<sup>40</sup> However, surveys show that 80% of Aboriginal peoples believe that a return to traditional practices is important. Furthermore, there are some segments of the medical community who have observed the spiritual element is missing from the Western approach to care and treatment.

<sup>&</sup>lt;sup>40</sup> A Royal Commission on Aboriginal Peoples in 1996 explored current practices in traditional medicines. The Commission found that traditional approaches were important to Aboriginal health and healing in areas such as childbirth, family violence, suicide, mental health and addictions.

Health Canada is currently developing a policy framework that will guide government and Western practitioners in how to work with and support traditional medicine and traditional healing practices. There are a number of practical considerations for policy development:

- Ensuring that First Nations, Métis, and Inuit peoples have control over traditional knowledge and the role of traditional healers;
- Finding a way to work with and provide support to the many Aboriginal groups across the country;
- Respecting jurisdictional issues. For example, introducing standards for traditional medicine would be outside the jurisdiction of the Government of Canada;
- Developing approaches to reimbursement so that traditional practitioners can receive payment in ways that are culturally-acceptable to them; and
- Determining how to connect with traditional healers and how to support the sharing of traditional knowledge.

#### 6.8 SUBSTANCE USE AND MENTAL ILLNESS

Substance use and mental health problems can increase the vulnerability of indigenous peoples to HIV/AIDS. In some countries, rates of substance use and mental health problems (e.g., depression, anxiety, post-traumatic stress disorder) are higher among indigenous peoples than among the non-indigenous population. For example, rates of new HIV positive cases resulting from IDU are considerably higher among Aboriginal men, women and Aboriginal youth when compared to rates in the non-Aboriginal population in Canada.

#### UNDERLYING CAUSES OF SUBSTANCE USE AND MENTAL HEALTH PROBLEMS

As discussed in Section 6.1 – Indigenous Determinants of Health - colonization is seen as an important underlying cause of both substance use and mental health problems among a large percentage of indigenous peoples because of its destructive effect on the social fabric and traditions of their communities. As a result, overall, indigenous peoples experience higher rates of substance use and inequitable access to health care.

#### **EFFECTS ON MENTAL HEALTH**

Colonization, stigma, and discrimination experienced by indigenous peoples have had a strong impact on the mental health of indigenous peoples. In order to cope with depression, disassociation or suicidal ideation, some may self-medicate with drugs or alcohol. Poverty combined with substance use or mental health problems may make it difficult to access safe, stable housing and other basic necessities. As a result, some of those affected may become homeless, street-involved and/or involved in sex work to survive. All of these factors significantly increase vulnerability to HIV, hepatitis C (HCV) and other sexually transmitted and blood-borne infections (STBBIs).

#### MENTAL HEALTH EFFECTS OF AN HIV POSITIVE DIAGNOSIS

The stigma of an HIV positive diagnosis is added on top of the stigma and discrimination regularly experienced by indigenous peoples because of their indigenous background. This added stigma can create a strong fear of disclosure of an HIV positive status, both within a community where it is difficult to maintain confidentiality and in health care settings. This further isolates indigenous PHAs, increasing their susceptibility to mental health problems such as depression, decreasing their quality of life and creating a barrier to seeking needed supports to stabilize their health. Indigenous PHAs may have had negative experiences in the past with government services or the health care system. For this reason, they may not trust doctors and may choose to not follow recommended treatment or access other supports offered.

#### APPROACHES TO TREATMENT OF SUBSTANCE ABUSE

Participants discussed the importance of using approaches to treat substance abuse for indigenous peoples that:

- Address the underlying causes of substance abuse and mental health problems
- Use an indigenous understanding of holistic health and cultural traditions
- Break the cycle of shame and blame experienced by indigenous peoples
- Open dialogue about sex and healthy sexuality
- Address co-infection of HIV, HCV and other STBBIs

In Australia, a harm reduction approach<sup>41</sup> is supported nationally and by state governments. Nationally, harm reduction is supported through the Office of Aboriginal and Torres Strait Islanders Health, working in partnership with community-based organizations. The Government of Australia is about to release the 3rd National HIV/AIDS Strategy for Aboriginal and Torres Strait Islanders population.

Other approaches discussed by participants included:

- Using treatment models that provide mentors to help end substance use and mental health problems;
- Investing in efforts to reduce the stigma against indigenous PHAs, including people who
  inject drugs, women and gay, lesbian, bisexual, transgender and two-spirited persons
  (within communities, the treatment system and broader society);
- Starting early with indigenous children and youth to build a positive self-image as the basis for informed choices; and

<sup>41</sup> Harm reduction is any program or policy designed to reduce drug-related harm without requiring the cessation of drug use. This separates harm reduction clearly from zero tolerance approaches to drug use. Harm reduction is a holistic approach that may include the individual, the family, community or society. From CAMH and Harm Reduction: A Background Paper on its Meaning and Application for Substance Use Issues. Prepared by Patricia Erickson, Jennifer Butters, Krystina Walko (Coordinators), Special Ad Hoc Committee on Harm Reduction; Centre for Addiction and Mental Health; University of Toronto; Canada; 2003.

• Ensuring adequate disability coverage, health insurance and supports for indigenous PHAs unable to work and/or living with substance use or mental health problems.

#### HIV AND HEPATITIS C INFECTION OF PEOPLE WHO INJECT DRUGS IN PRISONS

Participants discussed risk of infection and the HIV/AIDS response in the justice system. There are high rates of HIV/AIDS and HCV among prisoners in some countries, a significant proportion of whom are indigenous peoples. For example, in Australia, Aboriginal and Torres Strait Islander peoples represent a significant proportion of the prison population. There is a significant proportion of this group who are people who inject drugs, sometimes re-using syringes. They are therefore at increased risk of HIV and/or HCV infection.

In some jurisdictions, prisons have introduced needle exchange programmes to prevent HIV and HCV infection among the prison population. However, in other jurisdictions, government policies do not support this type of intervention. Greater efforts are needed to prevent and control HIV/AIDS in this population group.

In Canada, issues of abuse within Aboriginal families have been brought to the surface over the last decade. The legacy of the residential school experience, including sexual and other forms of abuse are affecting generations of Aboriginal families, increasing rates of incarceration and vulnerability to HIV infection. As part of a community-based response to help break the cycle of abuse and violence from being passed from generation to generation, Aboriginal communities and community-based organizations are developing culturally appropriate holistic models of treatment for Aboriginal victims and offenders, with a focus on healing families.

The approach taken is one that addresses the root causes of criminal activity and proactively engages offenders, victims and families to break the cycle of abuse. Communities engaged in these healing approaches have seen benefits in terms of significantly reduced criminal activity, improved physical and mental health of individuals, attainment of higher education and an increase in positive parenting.

#### 6.9 CO-INFECTION

Rates of tuberculosis (TB), HCV and sexually-transmitted infections (STIs) are higher among indigenous peoples than non-indigenous peoples. Data from a number of countries indicates increasing rates of TB, HCV and STIs among indigenous peoples.<sup>42</sup> The risk of HIV infection is five times greater with the presence of co-infection, which weakens the body's barriers to the virus. The presence of STIs is also a marker for unsafe sexual practices and increased risk of infection.

A holistic approach is needed to understand co-infection and the increased vulnerability of indigenous peoples. It requires involving a range of medical specializations and treatment

<sup>42</sup> In Canada, there has been an increase in the percentage of total reported cases of chlamydia, gonorrhea and infectious syphilis among Aboriginal peoples. Rates of newly diagnosed and reported cases of HCV were between 4.1 to 5.3 times higher among Aboriginal peoples compared to the non-Aboriginal population. IDUs accounted for the majority of diagnosed and reported HCV infections among Aboriginal persons (72.3% of cases). Between 3% and 15% of TB cases are infected with HIV, with HIV/TB more common in persons born outside Canada, in Aboriginal persons and in those with a history of IDU. Between 1997 and 2008, 25% of TB-HIV co-infected cases were among Aboriginal persons compared to 22% among Canadian-born non-Aboriginals and 51% among those born outside of Canada.

approaches, as well as a good understanding of the underlying conditions that increase the risk of infection among indigenous peoples, such as the impacts of colonization, poverty, low education; poorer general health; limited housing and/or homelessness; and unemployment (see Section 4.1 – Indigenous Determinants of Health).

#### **APPROACHES TO PREVENTION AND TREATMENT OF CO-INFECTION**

Participants discussed opportunities to strengthen approaches to preventing and treating HIV co-infections among indigenous peoples. These included:

- Overcoming historical/cultural experience of stigma, and management of chronic disease<sup>43</sup>;
- Supporting the development of community-specific, culturally-relevant programmes that increase community control over their health;
- Taking action on broader social and economic inequality that creates the conditions which increase indigenous peoples' vulnerability to HIV co-infection;
- Providing funding support for co-infection approaches;
  - ✓ Combining HIV and STI, HCV and TB counselling and testing, where appropriate, to increase screening rates;
  - ✓ Using integrated approaches that offer testing, treatment and referrals at one location for HIV, STIs, HCV and TB;
  - ✓ Involving indigenous PHAs in approaches to prevention, treatment and care of HIV coinfections; and
  - ✓ Addressing stigma and discrimination experienced by indigenous PHAs with HIV coinfections.

#### 6.10 RESEARCH, SURVEILLANCE AND DATA COLLECTION

Comprehensive data builds the foundation for all HIV/AIDS research, prevention, treatment, care and support initiatives. According to UNAIDS, very few countries have any reliable national surveillance data to indicate the true level of HIV infection among indigenous peoples.<sup>44</sup> Participants discussed the limitations of current systems for surveillance and data collection, noting how indigenous peoples are often invisible in reported statistics. Discussion focused on the importance of working toward disaggregated data that can support a more equitable and effective HIV response for indigenous peoples. Participants also discussed a range of factors that impact data collection, analysis and reporting.

#### **DISAGGREGATION OF INDIGENOUS HIV/AIDS DATA**

The UN Committee on Economic, Social and Cultural Rights and other human rights treaty

<sup>&</sup>lt;sup>43</sup> For example, many Aboriginal peoples in Canada were taken from reserves/communities when they were found to have TB, and shipped away to sanatoriums. If they came back to their communities, they were disassociated, similar to the residential school experience.

<sup>&</sup>lt;sup>44</sup> UNAIDS, Special Theme: the Millennium Development Goals and Indigenous Peoples: Redefining the Goals, Information Received from the United Nations system, E/C.19/2006/6/Add.10, 2006, p. 5

bodies ask that member countries provide disaggregated data on vulnerable groups as part of standard monitoring and reporting processes on HIV/AIDS and other indicators of health and development. Disaggregated data:

- More clearly identifies the scale of the HIV epidemic and its impact among indigenous peoples, especially women;
- Helps to uncover patterns and trends in sub-populations which might otherwise be lost in aggregated data;
- Provides information about specific population health needs and underlying social determinants of health to target the response;
- Supports the development of appropriate policies and programs, guides the equitable investment of resources and reduces health disparities; and
- Enhances community capacity to respond.

At this time, there is limited collection and reporting of disaggregated data on indigenous peoples and HIV/AIDS. A 2005 UNPFII report found that indigenous peoples were not specifically discussed in the context of meeting MDG  $6^{45}$  in any of the nineteen country reports reviewed.

Countries that do provide specific surveillance information on indigenous peoples note the limitations of the data resulting from a variety of problems, including inadequate information on ethnicity. For example, in Canada, from 1998 to the end of 2006, ethnicity data was only reported for 29.2% of HIV test records, and is not available for all provinces and territories.

Despite gaps and challenges with producing disaggregated data, an overview of Canada's national surveillance system was shared and discussed as a best practice example. The system has some ability to present disaggregated HIV and AIDS data describing specific population sub-groups. Disaggregation can be done at many levels, e.g., indigenous group, gender, age, location, socio-economic status and HIV exposure category.<sup>46</sup>

Participants identified some common challenges in collecting and analyzing disaggregated indigenous data on HIV/AIDS, including:

- Serious issues with data comparability both within countries and between countries, e.g., inconsistencies in data collection, completeness, analysis, interpretation, dissemination, ownership, control;
- Inadequate level of disaggregation and/or common identifiers, e.g., ethnicity data is not uniformly reported;

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<sup>&</sup>lt;sup>45</sup> MDG Goal 6 is aimed at halting and beginning to reverse the spread of HIV/AIDS

<sup>&</sup>lt;sup>46</sup> The PHAC HIV/AIDS surveillance system uses HIV/AIDS case report data, the "track" systems (behavioural and HIV prevalence data for at-risk populations) and national HIV/AIDS estimates. Among others at-risk populations, the track systems focus on data collection from people who inject drugs (I-Track), men having sex with men (M-Track), and Aboriginal peoples (A-Track).

- Inaccuracy in identity and ethnicity, e.g., status, registration and government identification of indigenous peoples, definitions, terminology, specificity of tribal or ethnic groups;
- Legitimacy of data, e.g., do research goals and methods match community needs? are research processes culturally sensitive and participatory? is the data of value/useful?
- Limitations of small sample size, e.g., disaggregation is only possible at the national level which limits regional policy and program development;
- Challenges with data access, e.g., establishing respectful practices for collection, production, gate-keeping and use of information among stakeholders such as indigenous communities, researchers and government; and
- Challenges due to the mobility of indigenous populations.

#### IMPACT OF STIGMA AND CULTURAL TABOOS

HIV surveillance data do not take into account those who do not undergo HIV testing, creating a situation of under-reporting. Some indigenous peoples may mistrust government and non-indigenous providers, and will therefore not seek out testing, advice or treatment. Data is also affected by past experiences of stigma and discrimination. For example, an indigenous person may choose not to provide optional ethnic information during an HIV/AIDS test due to:

- Mistrust of the system based on historically paternalistic structures; and
- Fear of cultural taboos associated with an HIV positive status.

#### POTENTIAL FOR DATA REPORTING TO INCREASE STIGMA AND DISCRIMINATION

The absence of relevant HIV/AIDS data can lead to neglect and invisibility and, therefore, deepen marginalization. However, reporting of high HIV/AIDS incidence rates has the potential to further stigmatize indigenous peoples, creating the false perception of a threat or burden to the larger population. Some researchers purposefully do not separate out HIV incidence in indigenous populations to avoid creating further stigma.

To address this problem, participants discussed the importance of accuracy, balance and sensitivity in reporting. A holistic approach to data interpretation and sharing of results presents data in the context of the social determinants of health that cause disease. Sharing this knowledge may create opportunities for dialogue on the increased vulnerability of indigenous populations to HIV/AIDS and positively influence research, policy and programme development.

#### DATA ON INDIGENOUS PEOPLES WHO REPRESENT A LARGE PART OF THE POPULATION

In some regions, indigenous peoples represent a significant part of the national population. For example, 55% of Bolivia's population is identified as indigenous, 45% in Peru, and 40% in Guatemala. In these cases, there has been a debate about whether a unique indigenous approach to HIV/AIDS is necessary. However, evidence indicates that indigenous peoples are still highly vulnerable in these countries, with poorer health status and compromised rights,

including their right to health.

#### 6.11 OPPORTUNITIES FOR POLICY AND PROGRAMMATIC RESPONSE

Participants discussed opportunities for policy and programmatic response to HIV/AIDS among indigenous peoples. In order for meaningful change to occur, there is a need for action at both the international and the national level.

#### LEVERAGING INTERNATIONAL INSTRUMENTS TO PROMOTE INDIGENOUS PEOPLES' RIGHTS

Participants discussed how best to leverage international policy instruments designed to promote and ensure the rights of indigenous peoples. Over the past 20 years, indigenous peoples have worked with international bodies and state governments to develop international instruments for the protection of the their rights, such as the International Labour Organization's (ILO) Convention 169 and the United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP).

The UNDRIP is a key instrument and tool for raising awareness on, and monitoring progress of, indigenous peoples' situations and the protection, respect and fulfillment of indigenous peoples' rights. It is intended to help operationalize a human rights-based approach to development as it applies to indigenous peoples. By setting out minimum international standards for the protection and promotion of the rights of indigenous peoples, it serves as a framework to guide states, UN bodies, indigenous peoples and civil society in the re-design of laws, policies and programmes for indigenous peoples.

A number of articles in the UNDRIP can be specifically applied to guide international, state-level and civil society actions to reduce the vulnerability of indigenous peoples to HIV/AIDS and to ensure self-determination in developing culturally-appropriate and culturally-relevant policy and programmatic responses:

- Article 21 outlines the right of indigenous peoples, without discrimination, to the improvement of their economic and social conditions, including in the areas of education, employment, vocational training and retraining, housing, sanitation, health and social security. It calls on States to take effective measures and, where appropriate, special measures to ensure continuing improvement of their economic and social conditions, with particular attention to the rights and special needs of indigenous elders, women, youth, children and persons with disabilities.
- Article 23 outlines the right of indigenous peoples to determine and develop priorities and strategies for exercising their right to develop health, housing and other economic and social programmes affecting them and, as far as possible, to administer such programmes through their own institutions.
- Article 24 outlines the right of indigenous peoples to traditional medicines and to maintain health practices, including the conservation of vital medicinal plants, animals and minerals and the right of indigenous individuals to access, without any discrimination, all social and health services. It calls for States to take the necessary steps to ensure an equal right to the enjoyment of the highest attainable standard of physical and mental health.

UNDRIP and ILO Convention 169 are mutually reinforcing. Convention 169, adopted at the 1989 International Labour Conference, is an international treaty aimed at ensuring equal rights of indigenous peoples, outlining standards of respect for indigenous peoples' culture, spirituality, social and economic organization and identity. Convention 169 includes specific health components that relate to equal rights of indigenous peoples to culturally-relevant HIV/AIDS prevention, testing, treatment and support. Both instruments are intended to be used to hold states accountable and they serve as sources of international law that can be invoked in judicial proceedings at the national level.

As of 2007, 143 countries had ratified the UNDRIP and many had also ratified ILO Convention 169. Campaigns for ratification in themselves provide platforms for advancing indigenous peoples' issues, helping to create consensus and build shared commitment. Participants also talked about the value of engaging the UN Special Rapporteur on the Right to Health in influencing national governments to ratify these international treaties, noting his efforts in drawing international attention to the inequities in health and access to health care experienced by indigenous peoples.

While ratification provides a commitment-based platform for establishing cooperative relationships between indigenous peoples and national governments, dialogue participants noted the serious limitations to date of these international instruments in ensuring indigenous peoples' rights are respected, even in countries that have ratified.

Given these limitations, participants called for the creation of operational tools that can be used to hold states accountable for ensuring equitable access of indigenous peoples to culturally-appropriate and culturally-relevant HIV/AIDS prevention, testing, treatment and support. They also called for the ILO to organize a forum on indigenous HIV/AIDS issues, pursuant to the health components of Convention 169.

#### INTEGRATION OF HIV/AIDS AND INDIGENOUS PEOPLES' ISSUES AT THE INTERNATIONAL LEVEL

Participants discussed how international fora focused on the rights of indigenous peoples and international AIDS agencies could play important roles in mobilizing action for an indigenous HIV/AIDS response. The global response to HIV/AIDS needs to include a call for the participation of indigenous peoples in the development of solutions and strategies for all nations. A specific declaration is needed by UNAIDS and other HIV/AIDS organizations to prioritize the involvement of indigenous peoples and to set specific targets for reducing rates of HIV/AIDS among indigenous peoples.

The United Nations Permanent Forum on Indigenous Issues (UNPFII), an advisory body to the Economic and Social Council,<sup>47</sup> has repeatedly emphasized the importance of a rights-based approach to development, including universality, equality, participation and accountability in working with indigenous peoples to achieve the MDG goals, including MDGs for HIV/AIDS. However, to date, UNPFII has not taken up the role of advocate within the UN system to push

<sup>&</sup>lt;sup>47</sup> The mandate of the UNPFII is to discuss indigenous issues related to economic and social development, culture, the environment, education, health and human rights. An Inter-Agency Support Group on Indigenous Issues (IASG) was established to support and promote the mandate of the UNPFII within the UN system and to support indigenous-related mandates throughout the inter-governmental system. It allows the UN system and other intergovernmental organizations to analyze recommendations made by the UNPFII with a view to facilitating comprehensive and coordinated responses to the UNPFII.

for structural changes to development programmes and policy processes to ensure an equitable HIV/AIDS response inclusive of indigenous peoples. Participants identified an opportunity for UNPFII to work in partnership with the newly established International Indigenous HIV/AIDS Working Group and other players to lobby UNAIDS to:

- Identify indigenous peoples as a priority group;
- Call for states to develop national strategies for HIV/AIDS and indigenous peoples; and
- Advocate for AIDS service organizations to develop culturally-appropriate, culturally-relevant services for indigenous peoples in partnership with indigenous communities' representatives.

The UNPFII representative at the dialogue indicated that Participants recommended that this Dialogue report be included as part of the next meeting agenda of UNPFII. The UNPFII representative who participated in the Dialogue offered to champion key Dialogue recommendations within the UNPFII.

#### CAPACITY-BUILDING TO INTEGRATE HIV/AIDS AND INDIGENOUS PEOPLES' ISSUES

Participants discussed the importance of building capacity to integrate HIV/AIDS and indigenous peoples' issues, both in terms of strengthening working relationships and in terms of identifying resources (people and funds) to support an effective indigenous HIV/AIDS response.

For example, development programmes to date have not specifically identified inclusion of indigenous peoples among the priority populations to be targeted by governments that receive funding. Few national governments have developed national strategies or funding programs for HIV/AIDS and indigenous peoples, and many indigenous communities have been excluded from access to culturally-appropriate and culturally-relevant HIV prevention campaigns, testing, treatment and support.

Participants discussed the need for a shift in the policies and practices of international bodies and national governments. For example, at the international level the Global Fund to Fight AIDS, Tuberculosis and Malaria could increase funding for projects specifically targeting indigenous peoples. Similarly, global and regional funding bodies could require the inclusion of gender and ethnicity in their funding agreements.

At the national level, indigenous and HIV/AIDS non-governmental organizations/networks, with the support of UNAIDS, could take steps to ensure that national strategies for HIV/AIDS and indigenous peoples are developed that are responsive to emerging issues in the HIV/AIDS epidemic (e.g., increasing rates of HIV infection among indigenous peoples, women, youth, people who inject drugs, prison populations, etc.), including commitments to indigenous-specific public health programmes and culturally-appropriate, culturally-relevant testing, treatment and supports.

In working toward more equitable practices, national governments could be encouraged and supported in training indigenous public health officers who bring knowledge of cultures and traditional health practices, ensuring that they have access to salaried positions in national health services.

#### MEANINGFUL INVOLVEMENT OF INDIGENOUS PEOPLES AND PHAS

Few indigenous peoples have strong representation in national political institutions, nor are they engaged as true partners in global HIV/AIDS control efforts. Increased participation in policy-making and real engagement of indigenous peoples has the potential to significantly reduce the impact of HIV/AIDS on communities.

Better cooperation between indigenous peoples, government and institutions is required, with indigenous peoples supported in identifying the needs of their communities, finding solutions and implementing policies and programmes. In order to achieve better cooperation, trust-building is needed between indigenous peoples, international bodies, national governments and institutions. Trust-building is necessary to overcome past experiences of exclusion, inequitable policies and practices, and a lack of respect for indigenous world views, perspectives and traditions.

As well as ensuring active participation of indigenous peoples, participants affirmed the importance of meaningfully involving PHAs, in keeping with the GIPA principle (Greater Involvement of Persons Living with HIV/AIDS).

Specific suggestions for more meaningful involvement were made, such as:

- Including indigenous caucus meetings on the agenda of all fora related to indigenous issues and HIV/AIDS;
- Ensuring that fora help to build the skills, experience, and knowledge of indigenous peoples and PHAs to participate meaningfully at every stage of research, policy and programme development processes; and
- Expanding opportunities for the involvement of indigenous PHAs within national HIV/AIDS movements.

As international bodies and state governments have limited experience with involving indigenous peoples and indigenous PHAs, participants suggested developing and distributing guidelines on overcoming barriers to indigenous participation. These guidelines could include approaches to seeking the participation of youth and elders in dialogues and at policy tables to creatively inform national strategies for HIV/AIDS and indigenous peoples.

Indigenous world views, perspectives and experiences are often excluded from HIV/AIDS reports and information. To overcome this, participants suggested using culturally-appropriate and culturally-relevant models/stories to organize and present issues at the regional, state and community level.

#### SHARING OF KNOWLEDGE AND WISE PRACTICES

In areas such as research, surveillance and data collection, there is a growing body of

knowledge about modes of transmission of HIV infection and the impact of HIV/AIDS on indigenous communities. There are a growing number of wise practice examples in areas of HIV/AIDS prevention, testing, treatment and support for indigenous peoples, including those specific to MSM, women, youth and people who inject drugs. However, to date, there has been limited sharing of knowledge and wise practices.

Examples of wise practices were shared by participants throughout the dialogue and are included throughout this report. A specific list of resources and wise practices captured through the dialogue is also included in Appendix E. In addition to specific project examples, some broad approaches to HIV/AIDS prevention, testing, treatment and support were presented. These included:

#### Brazil Experience – Public Health

Priority actions in public health districts of Brazil include the provision of condoms, taking an STI prevention approach, offering diagnosis and preventing the vertical transmission of HIV and syphilis. The following guidelines for HIV prevention among indigenous peoples are being followed:

- Organizing meetings with indigenous leaders to identify the problems in their communities and to discuss prevention work to be developed;
- Ensuring the transmission of knowledge on prevention is done using culturally appropriate-language, for example, through images and symbols;
- Introducing prevention approaches that consider traditional knowledge;
- Enhancing the role of the Indigenous Health Worker;
- Promoting the effective participation of the community in carrying out prevention activities and follow-up that are attentive to local cultural beliefs (e.g., condom use remains an unusual practice among indigenous peoples);
- Considering how to support women in negotiating condom use;
- Ensuring quality care, monitoring and support of pregnant women throughout the prenatal period and childbirth;
- Informing the community about the risk of mother-to-child HIV transmission through cross-feeding; and
- Using a primary care delivery approach at the district and local level to reach indigenous peoples living in diverse, remote locations.

#### Canadian Experience - Healthy Sexuality

Community-based indigenous programmes have developed best practices for working with indigenous communities on issues related to healthy sexuality. These include:

- Considering how healthy sexuality is practiced both on-reserve (rural) and off-reserve, regardless of sexual orientation;
- Promoting understanding of Aboriginal world views, attached to culture, tradition, languages and being connected to the environment;
- Re-educating indigenous peoples at all stages of the lifecycle about the role of women and their value to others;
- Being critical of the Indian Act, which institutionalized European gender roles and traditions of heterosexual marriage (indigenous status, rights and land title could only be legally extended to children through marriage)
- Going back to being non-shame-based communities in teachings and interactions; and
- Reclaiming traditional teachings, which encouraged healthy sexuality.

#### United States Experience – Indian Health Service

The ecological model of public health is being used by the Indian Health Service in the US with some success. It identifies the various levels where interventions can be taken to prevent HIV/AIDS or reduce its impact. Often there is limited focus on approaches that impact the broad socio-cultural environment in favour of a focus on the individual. However, the Indian Health Service is making efforts to work at this broader level. The levels, from highest to lowest level of influence, are:

- Broad socio-cultural/traditionalism/spiritual (e.g., broad norms of sexual activity, stigma, substance use);
- Constructed environment (e.g., systems, government and tribal policies, leadership);
- Community (e.g. support structure, PHAs, traditional healing);
- Clinic/Facility (e.g., access, training, culturally-appropriate services); and
- Individual (e.g., biological/genetic, individual behavior, barriers, treatment, care).

The Indian Health Service is moving forward with the following strategies to reduce HIV/AIDS:

- Reducing health disparities in HIV by:
  - ✓ Increasing universal screening (improved estimate of HIV burden in urban/rural communities)
  - ✓ Reducing stigma by normalizing HIV:
- Partnering with tribes;
- Improving linkages to care from rural locations;
- Networking all Indian Health Service/Tribal /Urban Providers to mobilize resources;
- As data improves with surveillance, analyzing and comparing communities; and
- Participating in the US National HIV Strategic Plan.

Participants recommended putting in place a range of formal and informal mechanisms to facilitate an ongoing exchange of knowledge and wise practices, including:

- Sharing information and examples presented at the dialogue through dissemination of this dialogue report;
- Sharing formal policy papers and evaluation reports through the informal network of dialogue participants;
- Synthesizing and sharing final reports of the indigenous satellite meetings held in conjunction with recent International AIDS Conferences (e.g., Toronto, Mexico);
- Supporting an exchange of experience and knowledge among indigenous communities;<sup>48</sup> and,
- Recognizing and supporting the important role of traditional medicine in the response to HIV/AIDS among indigenous peoples and documenting examples of successful cooperation between Western and traditional medicine to support indigenous PHAs.

#### 7.0 CONCLUSION AND NEXT STEPS

Indigenous caucus members expressed a strong commitment to making a difference for indigenous peoples in their communities impacted by HIV/AIDS. They commended the support and initiative of Health Canada in convening the meeting, at the same time emphasizing the importance of securing broader support from a wide range of international agencies and national governments. Through the dialogue, new connections among indigenous peoples' networks were established, along with a mechanism for sustaining them through the IIHAWG. Opportunities for strategic partnerships between indigenous peoples' networks, international bodies, national governments and youth representatives were initiated. In addition to the detailed recommendations, the following immediate commitments were made for next steps.

#### 7.1 INTERNATIONAL INDIGENOUS HIV/AIDS WORKING GROUP (IIHAWG)

The IIHAWG was identified as an important nucleus for moving forward collectively to prepare for the International AIDS Conference in Vienna 2010 and beyond. The IIHAWG will develop its terms of reference and membership to ensure representation from other countries that did not participate in the dialogue, e.g., Mexico. The IIHAWG membership will allow for regional autonomy in the selection of members. Each country will appoint a female and male representative to participate, who will be responsible for identifying and bringing forward priority issues from their country.

The Canadian Aboriginal AIDS Network (CAAN) representative affirmed CAAN's commitment to ensuring that indigenous leadership will continue to sustain the work of indigenous peoples from the dialogue and beyond. CAAN received formal endorsement from the indigenous

<sup>&</sup>lt;sup>48</sup> For example, where communities have not yet begun to develop a response to HIV/AIDS, a dialogue could be organized to exchange experiences and to support the communities in finding solutions.

caucus at the dialogue to take on this leadership role.

CAAN will continue to work in collaboration with Health Canada and the Public Health Agency of Canada to ensure that indigenous voices are heard to support the development of programs and services in developing countries. As a first step, CAAN committed to sending out a media release about the dialogue and to seek funds to support the work of the IIHAWG.

#### 7.2 HEALTH CANADA

As conveners of the policy dialogue, Health Canada representatives responded to the emerging recommendations by identifying areas where Health Canada could make immediate commitments for follow up. The International Affairs Directorate would:

- Prepare a report from the dialogue and request that it be posted to various websites, including those of UNAIDS and UNPFII;
- Share the report with dialogue participants, relevant multi-lateral development organizations and the ministries of health of the countries of dialogue participants;
- Use the report as a means to communicate results within global HIV/AIDS networks at the international and national levels;
- Work with other Government of Canada departments to identify where dialogue recommendations can be moved forward domestically, using an Indigenous social determinants of health approach;
- Facilitate the engagement of Canada, including indigenous representatives, in the 2010 International AIDS Conference in Vienna, and ensure the dialogue recommendations are reviewed by those shaping the Government of Canada's involvement at the event; and
- Ensure that electronic copies of all documents and presentations from the conference are forwarded to dialogue participants.

#### **APPENDIX A**

## 5<sup>TH</sup> INTERNATIONAL POLICY DIALOGUE – HIV/AIDS AND INDIGENOUS PEOPLES

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#### **APPENDIX B**

# 5<sup>TH</sup> INTERNATIONAL POLICY DIALOGUE – HIV/AIDS AND INDIGENOUS PEOPLES October 21-23, 2009 - Ottawa, Canada

#### **LIST OF PARTICIPANTS**

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#### **Art Zoccole**

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# APPENDIX C

# 5<sup>TH</sup> INTERNATIONAL POLICY DIALOGUE – HIV/AIDS AND INDIGENOUS PEOPLES OCTOBER 21-23, 2009 NOVOTEL HOTEL 33 NICOLAS STREET - OTTAWA, CANADA

# AGENDA

	WEDNESDAY, OCTOBER 21, 2009
08:00 - 08:30	Registration
08:30 - 09:00	Open Prayers and Welcome to the Territory
	<ul> <li>Annie Smith St-Georges, Algonquin Elder</li> </ul>
09:00 – 09:20	Welcome
	<ul> <li>Karen Dodds, Assistant Deputy Minister, Strategic Policy Branch, Health Canada</li> </ul>
09:20 - 09:50	Key-note Presentation:
	Human Rights and Indigenous Persons
	<ul> <li>Treaty 6 International Chief Wilton Littlechild, Commissioner, Truth and Reconciliation Commission</li> </ul>
09:50 - 10:10	Plenary Presentation:
	Indigenous Social Determinants of Health and HIV/AIDS
	<ul> <li>Margo Greenwood, Associate Professor, University of Northern B.C.</li> </ul>
10:10 – 10:30	Break
1030 - 12:00	Facilitated Discussion on morning presentations
12:00 – 13:30	Lunch
12:45 – 13:15	CULTURAL PRESENTATION
	"Taking Action: Art and Aboriginal Youth Leadership in HIV Prevention"
13:30 – 15:00	Panel Discussion:
	Modes of Transmission Amongst Indigenous Populations: Variances in Risk Factors for Infection in Different Regions
	<ul> <li>Chris Archibald, Director, Surveillance and Risk Assessment Division, Public Health Agency of Canada</li> </ul>
	<ul> <li>Michael Costello, Anwernekenhe National Aboriginal &amp; Torres Strait Islander HIV/AIDS Alliance - AFAO Representative, Australia</li> </ul>
	<ul> <li>Willy Madariaga, Consejeria entre Pares, Personas viviendo con VIH/SIDA, Chile</li> </ul>
	<ul> <li>Karanga Morgan, Executive Director, Te Puawai Tapu Trust, New Zealand</li> </ul>
15:00 – 15:30	Break
15:30 – 17:00	Plenary Discussion:
	The Importance of Political Geography in the HIV/AIDS Epidemic Amongst Indigenous Populations
	<ul> <li>Scott Giberson, National HIV/AIDS Principal Consultant, Indian Health Services, United States</li> </ul>

	THURSDAY, OCTOBER 22, 2009
08:30 - 09:00	Opening Prayers and Blessings
	Sally Webster, Inuit Elder
09:00 - 10:30	Panel Discussion:
	Indigenous Women and HIV/AIDS
	Charlotte Reading, Associate Professor, University of Victoria, B.C.
	<ul> <li>Annmaree O'Keefe, Senior Strategic Advisor, CRCI, Australia</li> </ul>
	<ul> <li>Property Smith, Aboriginal Sex Workers Outreach Project, Maggie's Toronto, Canada</li> </ul>
	<ul> <li>Jessica Yee, Executive Director, The Native Youth Sexual Health Network, Canada</li> </ul>
10:30 - 11:00	Break
10:45 – 11:00	CULTURAL PRESENTATION
	Traditional Chilean Consecration Ceremony
11:00 – 12:30	Breakout Sessions
	Co-infections
	<ul> <li>Jackie Arthur, Acting Manager, Populations Section, HIV/AIDS Policy, Coordination and Programs Division, Public Health Agency of Canada</li> </ul>
	Traditional and Western Medicine
	<ul> <li>Kim Barker, Public Health Advisor, Assembly of First Nations, Canada</li> </ul>
	Louise Garrow, First Nations and Inuit Health Branch, Health Canada
	Research, Surveillance, and the Lack of Disaggregated Data
	<ul> <li>Susanna Ogunnaike-Cooke, Manager, HIV/AIDS Epidemiology Section, Surveillance and Risk Assessment Division, Public Health Agency of Canada; and</li> </ul>
	<ul> <li>Mubeen Aslam, Senior Epidemiologist, HIV/AIDS Epidemiology Section, Surveillance and Risk Assessment Division, Public Health Agency of Canada</li> </ul>
12:30 – 13:30	Lunch
13:30 – 15:00	Panel Discussion:
	Indigenous Youth and HIV: Activism, Best Practices, and Prevention
	<ul> <li>Jessica Yee, Executive Director, The Native Youth Sexual Health Network,</li> <li>Canada</li> </ul>
	Ezra Pride-Lee Black Bird
	Jasmine Redfern, YouthCo AIDS Society, Canada
15:00 – 15:30	Break
15:30 – 17:00	Breakout Sessions
	Addictions / Mental Illness
	<ul> <li>Ken Clement, Chief Executive Officer, Canadian Aboriginal AIDS Network, Canada; and</li> </ul>
	<ul> <li>LaVerne Monette, Executive Director, Ontario Aboriginal HIV/AIDS Strategy, Canada</li> </ul>

Stigma and discrimination  Apihaka Mack, Chairperson/President, Maori, Indigenous and South Pacific HIV/AIDS Foundation, New Zealand  Justice System  Ed Buller, Director, Aboriginal Corrections Policy, Public Safety Canada  FRIDAY, OCTOBER 23, 2009  Opening Prayers and Blessings  Reta Gordon, Métis Nation of Ontario  Openon 10:30  Plenary: Report back from yesterday's break-out sessions  Panel Discussion: Gender Identities and Sexual Diversity  Art Zoccole, Executive Director, 2-Spirited People of the 1st Nations, Canada  Ezra Pride-Lee Black Bird  Clive Aspin, Research Director, Menzies Centre for Health Policy, University of Sydney, Australia  10:30 - 11:00  Break  11:00 - 12:15  Panel Discussion:  International, Regional, and National Instruments, Documents, and Opportunities for Bettering the Response to HIV/AIDS Amongst Indigenous Populations  Flavio Nunes, National Health Foundation, Ministry of Health, Brazil  Annmaree O'Keefe, Senior Strategic Advisor, CRCI, Australia  Elisa Canqui Mollo, Co-Chair, United Nations Permanent Forum on Indigenous Issues, Bolivia  12:15 - 13:15  Lunch  13:15 - 14:45  Table Discussions: Where Next?  14:45 - 15:15  Plenary Discussions: Where Next?  Closing Address  Anne-Marie Robinson (Assistant Deputy Minister, First Nations and Inuit Health Branch, Health Canada)  16:30 - 17:00  Closing by Annie Smith St-Georges, Algonquin Elder		a. I
HIV/AIDS Foundation, New Zealand  Justice System		
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Art Zoccole, Executive Director, 2-Spirited People of the 1st Nations, Canada     Ezra Pride-Lee Black Bird     Clive Aspin, Research Director, Menzies Centre for Health Policy, University of Sydney, Australia  10:30 – 11:00  Break  11:00 – 12:15  Panel Discussion:     International, Regional, and National Instruments, Documents, and Opportunities for Bettering the Response to HIV/AIDS Amongst Indigenous Populations     Flavio Nunes, National Health Foundation, Ministry of Health, Brazil     Annmaree O'Keefe, Senior Strategic Advisor, CRCI, Australia     Elisa Canqui Mollo, Co-Chair, United Nations Permanent Forum on Indigenous Issues, Bolivia  12:15 – 13:15  Lunch  13:15 – 14:45  Table Discussions: Where Next?  14:45 – 15:15  Break  15:15 – 16:30  Closing Address     Anne-Marie Robinson (Assistant Deputy Minister, First Nations and Inuit Health Branch, Health Canada)	09:00 - 09:30	Plenary: Report back from yesterday's break-out sessions
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Sydney, Australia  10:30 – 11:00  Break  Panel Discussion: International, Regional, and National Instruments, Documents, and Opportunities for Bettering the Response to HIV/AIDS Amongst Indigenous Populations Flavio Nunes, National Health Foundation, Ministry of Health, Brazil Annmaree O'Keefe, Senior Strategic Advisor, CRCI, Australia Elisa Canqui Mollo, Co-Chair, United Nations Permanent Forum on Indigenous Issues, Bolivia  12:15 – 13:15  Lunch  13:15 – 14:45 Table Discussions: Where Next?  14:45 – 15:15 Break  15:15 – 16:30 Closing Address Anne-Marie Robinson (Assistant Deputy Minister, First Nations and Inuit Health Branch, Health Canada)		
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Opportunities for Bettering the Response to HIV/AIDS Amongst Indigenous Populations  Flavio Nunes, National Health Foundation, Ministry of Health, Brazil  Annmaree O'Keefe, Senior Strategic Advisor, CRCI, Australia  Elisa Canqui Mollo, Co-Chair, United Nations Permanent Forum on Indigenous Issues, Bolivia  12:15 – 13:15  Lunch  13:15 – 14:45  Table Discussions: Where Next?  14:45 – 15:15  Break  15:15 – 16:30  Closing Address  Anne-Marie Robinson (Assistant Deputy Minister, First Nations and Inuit Health Branch, Health Canada)	11:00 – 12:15	Panel Discussion:
<ul> <li>Annmaree O'Keefe, Senior Strategic Advisor, CRCI, Australia</li> <li>Elisa Canqui Mollo, Co-Chair, United Nations Permanent Forum on Indigenous Issues, Bolivia</li> <li>12:15 – 13:15</li></ul>		Opportunities for Bettering the Response to HIV/AIDS Amongst Indigenous
<ul> <li>Elisa Canqui Mollo, Co-Chair, United Nations Permanent Forum on Indigenous Issues, Bolivia</li> <li>12:15 – 13:15</li></ul>		Flavio Nunes, National Health Foundation, Ministry of Health, Brazil
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<ul> <li>Anne-Marie Robinson (Assistant Deputy Minister, First Nations and Inuit Health Branch, Health Canada)</li> </ul>	15:15 – 16:15	Plenary Discussions: Where Next?
Health Branch, Health Canada)	16:15 – 16:30	Closing Address
16:30 – 17:00 Closing by Annie Smith St-Georges, Algonquin Elder		

#### **APPENDIX D**

### 5<sup>TH</sup> INTERNATIONAL POLICY DIALOGUE – HIV/AIDS AND INDIGENOUS PEOPLES

# EXCERPT FROM TORONTO CHARTER<sup>49</sup> INDIGENOUS PEOPLES ACTION PLAN ON HIV/AIDS

#### **KEY PRINCIPLES**

Acknowledge that Indigenous Peoples have shared experiences relating to the AIDS epidemic and its impacts on our communities.

**AFFIRM** that the AIDS epidemic continues to have a devastating effect on our communities.

**ACKNOWLEDGE** that Indigenous Peoples have inherent rights which guarantee them good health and well-being.

**ACKNOWLEDGE** that the changing patterns of the HIV/AIDS epidemic are placing Indigenous Peoples at increased risk of HIV infection.

**RECOGNISE** that Indigenous Peoples have the right to determine their own health priorities.

REAFFIRM that Indigenous Peoples have the right to control all aspects of their lives, including their health.

#### RECOMMENDATIONS

Ensure the central participation of Indigenous Peoples in all programmes related to the prevention of HIV and programmes for the care and support of Indigenous Peoples living with HIV/AIDS.

Provide adequate resources to Indigenous Peoples to design develop and implement HIV/AIDS programmes.

Increase current resources so that Indigenous communities can respond in a timely and effective way to the demands placed on communities by the AIDS epidemic.

Ensure the process of participation of Indigenous Peoples in United Nations forums is strengthened so their views are fairly represented.

Incorporate this Charter in its entirety in all policy pertaining to Indigenous Peoples and HIV/AIDS.

Monitor and take action against any States whose persistent policies and activities fail to acknowledge and support the integration of this Charter into State policies relating to HIV/AIDS.

<sup>&</sup>lt;sup>49</sup> The Toronto Charter is an initiative of the Planning Committee of the International Indigenous Peoples Satellite at the 16th International AIDS Conference, 2006 and has been endorsed by Indigenous People around the world. Available on-line at: http://www.afao.org.au/view\_articles.asp?pxa=ve&pxs=86&id=598#chart