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United Nations Declaration on the Rights of Indigenous Peoples**

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**Indigenous Peoples and HIV:
Research and Community-Based Responses to Reduce HIV Disparities**

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**INDIGENOUS PEOPLES AND HIV:
RESEARCH AND COMMUNITY-BASED RESPONSES TO REDUCE HIV DISPARITIES**

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**A BRIEFING PAPER PREPARED FOR THE INTERNATIONAL EXPERT GROUP MEETING
“SEXUAL HEALTH AND REPRODUCTIVE RIGHTS: ARTICLES 21, 22(1), 23 AND 24 OF THE
UNITED NATIONS DECLARATION OF THE RIGHTS OF INDIGENOUS PEOPLES”**

**PERMANENT FORUM ON INDIGENOUS ISSUES
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I. BACKGROUND

This paper discusses research into HIV and indigenous populations, provides a review of past research and makes recommendations for future research efforts.

The paper presents a brief summary of findings from a comprehensive literature review and describes recent community-based responses to HIV that provide examples of culturally appropriate strategies to address the challenges associated with HIV in indigenous communities.

Information in this briefing paper is derived from a number of projects on which I have worked that include

- A comprehensive literature review of HIV and indigenous peoples in Australia, Canada, New Zealand and the United States;¹
- A tri-partite research collaboration into the impact of HIV on indigenous peoples in Australia, Canada and New Zealand;² and
- A study into the collection of ethnicity data related to sexually transmitted infections in a regional location in New Zealand.³

The paper draws on my personal and professional experiences as

- A community worker, government policy analyst, academic researcher;
- A Founding Member of the International Indigenous Working Group on HIV and AIDS;
- A Board Member of INA (Maori Indigenous and Pacific AIDS Foundation); and
- An indigenous person who has lived throughout the entirety of the AIDS epidemic with first hand experience of its impact as a resident of Australia, New Zealand and France.

¹ Negin, J., Aspin, C., Gadsden, T. and Reading, C. (In submission) HIV among Indigenous peoples: a review of the literature since the beginning of the AIDS epidemic. *Lancet Infectious Diseases*.

² Shea, B., Aspin C., Ward, J., Archibald, C., Dickson, N., McDonald, A., Penehira, M., Masching, R., McAllister, S., Smith, L., Halverson, J., Kaldor, J., Andersson, N. (2011) HIV diagnoses in indigenous peoples: comparison of Australia, Canada and New Zealand, *International Health*, 3 (3): 139-218.

³ Aspin, C., Sexton, K., Pirie, R., and Smith, L. T. (2010). *Monitoring sexually transmitted infections among Maori in the Bay of Plenty*. Hamilton: University of Waikato.

2. VULNERABILITY

Globally, indigenous peoples have poorer health status than their non-indigenous peers in the same country, with this being reflected in vulnerability to HIV.

As an example, in New Zealand, Maori were identified as vulnerable to HIV in 1992, nine years after the first notification of HIV in New Zealand.

Despite this early warning, little was done to collect information about rates of HIV among Maori until 1996 when the country's HIV and AIDS surveillance agency decided to begin collecting ethnicity data. Information about rates of HIV among Maori prior to this date was collected retrospectively.

3. DATA COLLECTION

Globally, there is limited information about the impact of HIV on indigenous populations, largely because of poor or non-existent data collection processes. This is further exacerbated by under- or mis-reporting of indigenous health data.

Even in countries with good data collection mechanisms, anomalies exist. With regard to sexually transmitted infections, including HIV, evidence shows that it is difficult to gain an accurate understanding of the extent to which these infections affect indigenous peoples because of poor reporting mechanisms.⁴

4. CURRENT HIV DISPARITIES

In locations where robust data collection processes are in place, significant HIV disparities exist between indigenous and non-indigenous peoples. As examples,

- In Canada in 2011, Aboriginal peoples made up 4.3% of the population, yet accounted for 12% of new HIV infections and almost 20 per cent of all AIDS cases.⁵
- In Australia, HIV diagnoses are significantly higher among Aboriginal and Torres Strait Islander females than among non-indigenous females.⁶
- In New Zealand, Maori men are more likely to test late for HIV, with this contributing to poorer health outcomes for Maori men than non-Maori men.⁷

⁴ Aspin, C., Sexton, K., Pirie, R., and Smith, L. T. (2010). *Monitoring sexually transmitted infections among Maori in the Bay of Plenty*. Hamilton: University of Waikato.

⁵ Public Health Agency of Canada. *Estimates of HIV Prevalence and Incidence in Canada 2011*. Ottawa, Canada: Health Canada; 2011.

⁶ Ward J, Akre SP, Kaldor JM. Guarding against an HIV epidemic within an Aboriginal community and cultural framework; lessons from NSW. New South Wales public health bulletin. 2010; **21**(3-4): 78-82.

⁷ Dickson NM, S.; Sharples, K.; Paul, C. Late presentation of HIV infection among adults in New Zealand: 2005-2010. HIV medicine. 2012; **13**(3): 182-9.

Table 1. Standardised rates of HIV diagnosis among the Indigenous peoples of Australia, Canada and New Zealand (AR/100,000)

	Australia		Canada		New Zealand	
	2004-2008		2004-2008		2004-2008	
	Male	Female	Male	Female	Male	Female
Indigenous	48.5	12.9	178.1	178.4	41.9	4.3
Non-Indigenous	50.6	4.4	49.2	9.04	44.5	2.5

Source: Shea, B., Aspin C., Ward, J. et al. (2011) HIV diagnoses in indigenous peoples: comparison of Australia, Canada and New Zealand, *International Health* 3: 193-198.

5. RESEARCHING INDIGENOUS PEOPLES

The history of indigenous peoples is replete with examples of inappropriate research into indigenous peoples.⁸ Much of this research has been conducted by non-indigenous researchers who have attempted to understand and explain the indigenous experience according to their own non-indigenous paradigms. As a consequence, this research has made little positive difference to improving indigenous health outcomes.

6. REVIEW OF THE LITERATURE ON HIV AND INDIGENOUS PEOPLES

Since the beginning of the AIDS epidemic, much time and effort has been devoted to research into indigenous populations and HIV yet these efforts have done little to reduce HIV disparities among indigenous peoples.

A recent literature review of publications related to HIV and indigenous peoples in Australia, New Zealand, Canada and the United States showed that research has been driven by the recognition that indigenous peoples are vulnerable to HIV, yet research findings have had little impact in improving health outcomes and reducing disparities (Negin et al, in press). Rather this research has served to reinforce colonialist views that indigenous peoples are weak and vulnerable, and in need of the “beneficent colonizer”. Greater benefit would be derived from recognizing the inherent strengths of indigenous peoples and the understanding the factors that promote self-determination and provide protection from HIV.

The review focused on literature from 1990 to 2013 that discussed HIV and indigenous peoples in Australia, Canada, New Zealand and the United States since the indigenous peoples of these countries share a common history of colonization, dispossession and marginalization.

⁸ Smith, L. T. (1999). *Decolonising Methodologies. Research and Indigenous Peoples*. London: Zed Books.

7. FACTORS THAT INCREASE VULNERABILITY TO HIV

The review identified a range of factors that increase the vulnerability of indigenous peoples to HIV.

Factors that were identified as contributing to vulnerability and risk of HIV included

- social and economic disadvantage;
- poor access to health services;
- high rates of injecting drug use ;
- high rates of sexually transmitted infections; and
- exposure to stigma and discrimination.

The high rates of STIs in many global communities increases HIV transmission risk and there needs to be concerted international efforts to address this issue, especially within indigenous communities and those vulnerable communities with high rates of STIs.

High rates of STIs have the potential to negatively impact on the rights of women to a healthy reproductive life since these can contribute to conditions such as pelvic inflammatory disease and ultimately infertility.

High rates of STIs, including HIV among indigenous women pose real challenges for governments and health service providers and have serious implications for the health and well-being of indigenous communities.

8. MISTRUST OF HEALTH SERVICES

Many of these factors contributed to high levels of mistrust of health services which in turn appears to be a major contributing factor to the high rates of late testing for HIV among Indigenous peoples and the subsequent poor health outcomes.

Factors associated with vulnerability included

- childhood sexual abuse had been experienced by women
- high levels of stigma and discrimination experienced by indigenous MSM
- poor access to services
- high levels of injecting drug use among indigenous populations

Several papers that informed the review indicated that indigenous peoples affected by HIV have a long and enduring history of mistrust of health services which results in poor access to health care, late testing for HIV, and poor or no care and support for people living with HIV.

9. PROTECTIVE FACTORS

Indigenous peoples are part of familial and cultural networks which need to be taken into consideration in the design and development of indigenous HIV prevention programs. People of all ages from youth to elders need to be involved in campaigns to prevent the transmission of HIV in indigenous communities.

Indigenous peoples and communities need to have access to supportive education and testing environments which recognize and respect indigenous cultural values.

10. INDIGENOUS DIVERSITY

After more than 30 years of the AIDS epidemic, it is clear that HIV is affecting indigenous communities in diverse and complex ways. In countries such as Australia and New Zealand, men who have sex with men continue to be the most affected group. In other countries such as Canada, HIV has disproportionately affected indigenous women.

In a number of countries, young indigenous peoples have higher rates of HIV than their non-indigenous peers.

11. COMMUNITY-BASED RESPONSES TO HIV

Community based responses to HIV provide a viable and realistic alternative to non-indigenous led initiatives to prevent the transmission of HIV among diverse indigenous populations.

In response to high rates of HIV among indigenous peoples, a number of innovative community-based initiatives have been developed, both within countries and internationally. In the process, a durable and sustainable network of people and communities has been established globally to raise awareness of HIV and its impact on indigenous peoples. In contrast to initiatives developed by non-indigenous agencies, these initiatives are led by indigenous peoples themselves and are firmly grounded within indigenous communities. These responses draw on the resilience and innate strengths of indigenous communities that have been passed down through many generations. Just as indigenous communities have shown remarkable resilience in the face of major trauma and upheaval throughout history, today we can see evidence of indigenous communities responding in a way that will ensure they overcome the challenges presented by HIV and AIDS. Three recent community initiatives provide clear evidence that, after three decades of HIV, indigenous communities are taking charge of strategies to prevent the ongoing transmission of HIV among Indigenous peoples and to provide care and support for those people affected by HIV.

The Toronto Charter: Indigenous Peoples' Action Plan on HIV and AIDS

The Toronto Charter is an action plan on HIV and AIDS for indigenous peoples around the world and was launched at the 16th International AIDS Conference in Toronto in 2006.⁹

The development of the Charter was led by the Planning Committee of the Indigenous Satellite meeting that took place in the lead up to the international conference. As part of this process, members of the committee consulted with indigenous communities in a number of countries, including Australia, Canada, New Zealand and the United States as well as with representatives of the United Nations Permanent Forum on Indigenous Issues.

Overwhelmingly, the Charter was endorsed at these meetings, with this support in evidence when the Charter was launched in Toronto in 2006. Overwhelming endorsement by the indigenous delegates at the Toronto AIDS Conference confirmed that there was a need for a document that could guide the development of HIV policy in the countries from which delegates came.

The Charter calls for a complete reorientation of the ways in which HIV care, support and prevention programs are conducted within indigenous communities around the world

⁹ The Toronto Charter is hosted by the International Indigenous Working Group on HIV and AIDS and can be viewed on their website (www.iiwgha.org)

and emphasises the need for indigenous peoples to be at the forefront of designing and implementing HIV programs for indigenous peoples.

The recommendations of the Charter are based on the acknowledgement that successful initiatives to overcome the impact of HIV in indigenous communities must be based on partnership and collaboration. The Charter calls on government agencies and HIV decision makers to:

- Ensure the central participation of indigenous peoples in all programs related to the prevention of HIV and programs 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 programs.
- 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.

Seven years after the launch of the Toronto Charter, there are indications that the Charter is having some impact at national and international levels. In New Zealand, the Charter features prominently in the work of INA and provided contextual information for recent successful government grant applications.

Internationally, the Charter informed discussions and outcomes of an international policy dialogue convened by Health Canada (Health Canada, 2009). And more recently, the Toronto Charter was tabled and discussed at a side event of a meeting of the United Nations Permanent Forum on Indigenous Issues.

The Toronto Charter is currently being reviewed and evaluated to ensure that it meets future needs of indigenous peoples and communities affected by HIV and AIDS.

International Indigenous Working Group on HIV and AIDS (IIWGHA)¹⁰

This working group was established soon after the Toronto Conference and to date, is made up of indigenous leaders from countries that include Australia, Bolivia, Brazil, Canada, Chile, Guatemala, Mexico, New Zealand and the United States.

A key role of the group is to build and consolidate international networks to increase awareness of HIV and to develop strategies to influence the development of indigenous HIV policy. The forum was established in response to increasing rates of HIV among indigenous peoples internationally and in the face of limited and inappropriate government response to HIV among Indigenous peoples in many parts of the world.

¹⁰ www.iiwgha.org

The high rates of HIV among the indigenous peoples of Canada provide a salient example of how inadequate government responses to multiple social and health risk factors can contribute to disproportionate rates of HIV among First Nations, Metis and Inuit peoples.^{11 12}

In response to the lack of national and international government action in the face of HIV-related challenges to the health of indigenous peoples, IIWGHA was established with the following objectives:

1. Increase the integration of HIV/AIDS and Indigenous peoples at the international level;
2. Improve meaningful inclusion of Indigenous peoples in research, policy and program development;
3. Ensure Indigenous peoples are more accurately represented in HIV/AIDS data collection;
4. Increase support for HIV capacity development;
5. Develop an Indigenous specific approach to the social determinants and health; and
6. Ensure that Indigenous and HIV/AIDS issues are presented at international AIDS conferences.

Since its inception, the IIWGHA has achieved significant success, both nationally within countries and internationally. Tangible achievements include the development and implementation of a strategic plan, as well as the development of an international indigenous HIV research plan, with these being underpinned by a robust network of indigenous researchers, communities and people living with HIV around the world.

This network has been responsible for coordinating and organizing international meetings that have brought people together from countries throughout the world. As a result, there has been a strong and visible presence of international AIDS conferences since the meeting in Toronto in 2006. This increased visibility of indigenous peoples at international meeting has been a driving factor in ensuring that indigenous peoples and HIV figure prominently on the agendas of these meetings.

¹¹ Craib, K. J. P., Spittal, P. M., Wood, E., Laliberte, N., Hogg, R. S., Li, K. et al. (2003). Risk factors for elevated HIV incidence among Aboriginal injection drug users in Vancouver. *Canadian Medical Association Journal*, 168(1), 19-24.

In New Zealand, a recently established national Maori community-based initiative demonstrates clearly that Maori are building strong networks to deal with the the impact of HIV on communities and individuals. INA (Maori, Indigenous and Pacific Island HIV/AIDS Foundation) is evidence of Maori resilience in the face of adversity. As well as providing significant local community development, INA has also established a strong and enduring international presence through their representation at international forums and networks. The work of INA is based on three key objectives:

1. To improve the quality of life for people living with HIV/AIDS
2. To improve the quality of information on HIV given to our communities
3. To advocate for the rights of all Indigenous peoples

The success of INA can be measured by the fact that they have achieved Government recognition in the form of a formal contract. Today, INA provides HIV services throughout New Zealand while maintaining a strong international focus which allows the organisation to play a valuable membership role in the International Indigenous Working Group on HIV and AIDS.

12. RECOMMENDATIONS TO REDUCE HIV DISPARITIES

It is imperative that HIV initiatives to prevent the ongoing transmission of HIV and to reduce HIV disparities, including research, must be based on appropriate community engagement in all HIV programs for the prevention of HIV and the care and support of people living with HIV. This needs to be reflected in HIV policy and practice at all levels of government and service provision.

Indigenous HIV research programs need to be driven by the needs of indigenous communities and these programs need to engage with indigenous peoples in ways that are respectful and which recognise the inherent strengths of indigenous peoples. Research must take a strengths-based approach rather than one that is based on deficit models.

Effective leadership at community and government levels is vital to reducing HIV disparities.

Indigenous peoples living with HIV have a key role to play in the design and delivery of programs. It is essential that indigenous HIV initiatives ensure that PLWHA are involved in programs in ways that recognize and acknowledge the diverse skills, experience and expertise that PLWHA bring to program delivery.

Since the inception of the AIDS epidemic, HIV has posed challenges that affect indigenous communities internationally. For indigenous populations, the international networks that have come together in response to HIV are fundamental to overcoming the challenges posed by HIV. These networks must be supported nationally and internationally to ensure the effectiveness of their work as we work together to overcome HIV, and ensure self-determination and the ongoing viability of indigenous communities for generations to come.

¹³ www.ina.maori.nz