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**Special theme: Millennium Development Goals and indigenous peoples: redefining Goals****Information received from the United Nations system****UNAIDS, Joint United Nations Programme on HIV/AIDS\*****Summary**

In respond to recommendations of the Permanent Forum on Indigenous Issues, UNAIDS provided background information on understanding of HIV/AIDS related issues among indigenous peoples, analysis on some key factors influencing vulnerability and impact of HIV and AIDS on indigenous peoples in the context of social, cultural and economic development. Examples of initiatives on HIV prevention among indigenous communities were presented. UNAIDS presented a few issues which are relevant to HIV prevention and AIDS care and treatment

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\* The present document was submitted late in order to ensure the inclusion of the most recent information.

among indigenous peoples to be discussed at the Forum, recommendations were also made to the Forum in this regard.

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## I. Introduction

1. This paper was prepared by UNAIDS at the request of the UN Permanent Forum on Indigenous Issues to assist the Forum in its discussion of issues relating to Millennium Development Goal [6 - Combat HIV/AIDS, malaria and other diseases](#) at its May 2006 meeting.

2. In talking about indigenous peoples, this paper draws upon the common understanding that has evolved in the international community of what is distinctive of indigenous peoples' experience. Central to this understanding is the notion that indigenous peoples are descended from the original inhabitants of a particular region, have a special attachment to that land and a belief system that flows from that attachment. It is an attachment which pre-dates the establishment of modern states and territories, and which in many cases has been dislocated by the establishment of these jurisdictions and by more recent economic development. Because the relationship between indigenous peoples and their land is often neglected by mainstream economic development, the threat posed to this fundamental part of indigenous culture is a feature of the modern experience of many indigenous peoples<sup>1</sup>.

3. Indigenous peoples seek to maintain the historical continuity of their connection to land, and the cultural identity that accompanies it, in the face of other cultures that have become dominant by reason of colonisation or occupation. In many countries, indigenous peoples are

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<sup>1</sup> References can be found in: The ILO Convention (No. 169) concerning Indigenous and Tribal Peoples in Independent Countries and *Study of the problem of discrimination against indigenous populations*, Jose R. Martinez Cobo, E/CH.4/Sub.2/1986/7 and Add. 1-4.

minorities and - lack a voice within mainstream political institutions. To this extent, the experience of indigenous peoples is often one of marginalization within the countries in which they live and limited participation in the political process. -They are excluded from the institutions that shape mainstream political, economic and social values.

4. How these factors play out in the day-to-day lives of indigenous peoples varies greatly across communities and countries. There are great differences in the extent to which particular indigenous communities have been able to maintain traditional ways of living including traditional beliefs and practices. Some indigenous peoples still live in their own self-contained communities, often geographically isolated from major urban centres. Others struggle to reconcile traditional communal ties and values with the economic and social realities of the country in which they live. While their indigenous heritage may remain a central part of their identity in each case, the impact this has on their lived experiences may be radically different.

5. For this reason, any discussion about indigenous peoples as a single group necessarily involves considerable generalization that does not do justice to the enormous diversity in indigenous culture and experience across the world. This must be borne in mind when reading this issue paper. Of course not all the issues discussed in this paper will be relevant to all indigenous peoples, nor will they affect them all in the same way. Nonetheless, the common themes in the experience of many indigenous peoples in different parts of the world shape how the HIV epidemic affects their lives and their communities. This paper explores those themes in

order to shed light on what can be done to reduce the spread and impact of HIV within indigenous communities.

## **II. What is known about the extent of HIV infection in indigenous populations?**

6. Very few countries have any reliable national surveillance data to indicate the true level of HIV infection among indigenous peoples. The available data are summarised in Appendix 1. Only some surveillance programmes record the ethnicity of those tested, and even where infection levels in specific ethnic groups are identified, there is limited information about the specific patterns of HIV risk and the way in which HIV affects those communities. As with all data about HIV incidence and prevalence, caution must be exercised in drawing conclusions about the level of HIV risk based only on the results of HIV tests carried out on selected segments of the population.

7. This is particularly so when trying to determine levels of HIV infection in marginalized groups, which is the case with many indigenous populations. Where people are geographically isolated, for example, or less able to access the health care system, they may be missed by many HIV testing programmes. Moreover, where stigma and discrimination are associated with indigenous status, there is a disincentive for indigenous peoples to disclose their status if asked. Social and cultural taboos may also discourage indigenous peoples from disclosing forms of behaviour that place them at risk of HIV infection, if those behaviours are considered unacceptable in their communities.

8. There may also be good reasons for investigators not wanting to target marginalized groups, such as indigenous peoples, for specific HIV data collection. In the case of groups that are already disadvantaged and subject to stigmatisation, the publication of data suggesting high levels of HIV infection within those groups can increase the stigma experienced by those groups, even though there might be high infection rates in other parts of the population as well. This concern has led some policy-makers to avoid policy interventions focusing specifically on HIV in indigenous peoples, and instead incorporate these initiatives in other programmes, such as those dealing with sexual health generally. The possible negative consequences of data collection highlight the need for any research into HIV in indigenous communities to be carried out with care in order to avoid causing unintended harm to the people concerned.

9. Just as the collection of data on HIV in indigenous communities may lead to stigma and discrimination, the absence of data can lead to neglect or invisibility. The absence of reliable data about HIV infection in indigenous populations has sometimes made it more difficult for concerns about the impact of the HIV epidemic on indigenous populations to be given priority on national and international policy agendas. There is a risk that resources will instead go to HIV programmes targeted at populations where better data exist to demonstrate already high levels of HIV infection. Jurisdictions need to strike a balance between policies that seek to protect indigenous communities from being incorrectly perceived as a HIV threat to mainstream communities and the need to have reliable data on the impact of HIV in indigenous communities that can be fed into planning and resource allocation processes.

10. In this context, however, it needs to be emphasised that the number of diagnosed cases of HIV is only one measure – and often not the best measure – of the HIV risk faced by a particular community. The global experience with the epidemic has made it clear that there are key factors that render some individuals and communities acutely vulnerable to HIV. Many, indeed most, of these risk factors are present in a large number of indigenous populations. They include poverty, marginalization, lack of political or social power, fragmentation of family and community relationships, geographical isolation, low literacy, poor general health, limited access to health care, drug use/injection and low individual and community self-esteem. Any one of these factors alone is enough to increase an individual or community's susceptibility to HIV infection. To have many of these factors present within one population group signals clear cause for concern about the impact of the HIV epidemic on indigenous populations, and highlights the challenges faced in trying to reduce its spread within these communities.

### **III. Examples of strategies, policies and initiatives focused on HIV in indigenous peoples**

11. Just as there has been little consistent data collection on HIV in indigenous populations, there have also been only a relatively small number of specific policies and programmes implemented to address the spread and impact of HIV within indigenous communities. A few countries have adopted national strategies covering HIV in their indigenous populations, but this has generally happened only in better-resourced countries, such as Canada and Australia. Many countries have done nothing to specifically address HIV issues in their indigenous

peoples, whilst a small number of countries have embarked on small-scale initiatives. In some places, community-based and other nongovernmental organizations have taken the lead in HIV prevention and care in indigenous communities, with greater or lesser degrees of government support.

12. It has not been possible within the scope of this paper to undertake a full review of all initiatives to date relating to HIV in indigenous peoples, and there would be value in studying these initiatives further to consider the lessons learnt from what has been done. Further readings and resource materials in this area are listed in Appendix 2. The following are examples of some of the key strategies and policies implemented to date.

- *Aboriginal Strategy on HIV/AIDS in Canada for First Nations, Inuit and Metis People, March 2003*

The strategy was developed by the Canadian Aboriginal AIDS Network, with funding from the Canadian Government, as part of the Canadian national strategy on HIV. It covers nine strategic areas, including community development, capacity building and training; sustainability, partnerships and collaboration; legal, ethical and human rights issues; engaging Aboriginal groups with specific needs; and holistic care, treatment and support.

- *National Indigenous Australians' Sexual Health Strategy, 1996-1999*

*National Aboriginal and Torres Strait Islander Sexual Health and Blood Borne Virus Strategy, 2005-2008*

Both these strategies address HIV in the context of indigenous sexual health generally and complement Australia's National Strategy on HIV. There was a deliberate policy decision to position indigenous HIV initiatives within a sexual and reproductive health approach to avoid further stigmatization of indigenous Australians and in recognition of the need for significant improvements in indigenous sexual and reproductive health.

- *The American Indian/Alaska Native Initiative, US Department of Health & Human Services*

The American Indian/Alaska Native Initiative is designed to integrate drug use and mental health services with HIV primary health care for American Indian and Alaska Native communities. Six demonstration projects and a technical assistance centre comprise this five-year initiative, which began in October 2002 and ends in September 2007. Since AI/AN agencies operate under a Federal policy that promotes self determination for American Indian and Alaska Native peoples, the technical assistance centre respects the interests of AI/AN projects to develop culturally appropriate solutions to community, tribal, and village issues and encourages solutions to come from the local level.

- *Indigenous Peoples' Development Plan – Guyana, 2004*

As part of the Guyana HIV/AIDS Prevention and Control Project, the Government of Guyana implemented the Indigenous Peoples Development Plan. The Plan identifies a range of factors that increase the vulnerability of indigenous communities in Guyana to HIV/AIDS, such as poverty, social disruption caused by mining, migration of young people, drug use, early sexual activity, and certain cultural beliefs and practices. Among the interventions proposed are distribution of material on HIV translated into indigenous languages, establishing voluntary counselling and testing centres close to indigenous communities, greater education for young girls, and community development projects for young indigenous people.

- *Health of the Indigenous Peoples Initiative – Pan American Health Organization Strategic Directions and Plan of Action, 2003-2007*

This Action Plan covers indigenous health generally, but includes issues relating to HIV, particularly access to care and essential drugs. It notes existing inequities in health status and access to health care between indigenous peoples in the Americas and other population groups, and outlines a plan of action to improve indigenous health status, including strengthening networks of inter-sectoral collaboration; incorporating indigenous perspectives and therapies in primary health care; promoting strategies that address the social exclusion of indigenous populations; and encouraging indigenous participation in the management of health services.

- *HIV/AIDS Project for Aboriginal Youth – Public Health Agency of Canada, 2005-2007*

This project, implemented in partnership with the Native Men's Residence in Toronto, aims to increase awareness of HIV and promote safer sex among homeless Aboriginal youth.

- *The Management of HIV/AIDS in Indigenous Primary Care Organisations, Australia*

This resource guide was developed a group of Indigenous Australians infected and affected by HIV. It was developed for use in remote and urban Aboriginal Medical Services and in other primary care services.

- *The Australian Federation of AIDS Organisations Aboriginal and Torres Strait Islander Gay, Sistergirl and Transgender HIV/AIDS – Sexual Health Project*

This long-standing government supported project was established in 1996 and supports the indigenous work of Australians national HIV nongovernmental organization. In an epidemic driven primarily by sex between men, the project focuses on indigenous gay men, sistergirls and transgendered people. In addition to health promotion activities and advocacy, the project provides cultural awareness training for non-indigenous HIV workers and HIV training for indigenous health workers.

#### **IV. Key Factors affecting the impact of the HIV Epidemic on Indigenous populations**

##### **(a) *The Relationship to Land***

13. If one of the key identifying characteristics of indigenous status is taken to be an attachment to ancestral land, then the displacement of that attachment due to economic and political developments in many countries of the world has a profound impact on the lives of indigenous peoples. Many indigenous communities are no longer able to live on the land from which they draw their cultural identity, and have been forced to abandon their traditional ways of living as a result. This, in turn, affects in many ways how the HIV epidemic may be experienced in those communities.

14. The devastating consequences of colonisation for the general health of most indigenous peoples has been well documented. Infectious diseases such as smallpox decimated many indigenous populations during the early phases of colonisation, and this has been followed by dramatic increases in chronic disease brought about by the disruption to traditional indigenous lifestyles. In particular, diseases such as diabetes and chronic heart disease are now prevalent in many indigenous communities as a result of poor diet and unhealthy lifestyles in people whose preferred way of living is no longer tenable.

15. The forced transition to a lifestyle more compatible with the demands of modern economies has usually involved a relinquishment, in whole or in part, of the attachment to ancestral land. While some indigenous communities now live on reservations or in enclaves established in an attempt to preserve traditional lands, the extent to which those communities are able to retain traditional lifestyles is severely curtailed. Poverty, unemployment, imprisonment, alcoholism and other drug use including injecting may be more common in some settings as extensively

documented and analysed in many studies (see references in the appendix 2). Moreover, the geographical isolation of these communities means that they have limited access to mainstream educational, health care and public health facilities. Each of these factors gives rise to heightened HIV risk.

16. Where the severing of their traditional relationship to land has resulted in the migration of indigenous peoples to urban areas, a similar range of social problems is evident. Indigenous communities within cities are generally marked by higher levels of poverty and other related consequences on health. - Their marginalization makes them more exposed to the risks of HIV transmission and harder to reach for HIV prevention and care.

17. Just as significant as the impact on lifestyle is the effect that dispossession from traditional land has had on the cultural and spiritual wellbeing of indigenous peoples. A community lacking in social cohesion, whose internal values are under threat, is not well-placed to address the impact of HIV infection. - Affected by the loss of land, territories and natural resources which are fundamental elements for them to sustain as peoples, many indigenous peoples' - social and cultural - capacity is also diminishing to address the challenges - of HIV within community and to take steps to address the factors that increase the likelihood of HIV transmission.

**(b) Poverty**

18. While there are of course exceptions, many indigenous communities are economically disadvantaged compared with other segments of the population. This is often a direct consequence of the disruption to subsistence on land that has characterised many indigenous cultures. The resulting loss of self-sufficiency has meant that many indigenous peoples are forced to - move away from their community in search of work. Low levels of formal education mean that indigenous peoples may find it more difficult to obtain secure work and are frequently employed in lower paid jobs with little access to employer supported health schemes. Many who migrate from their traditional rural homes to urban areas end up living in poverty in urban slums. Although no longer geographically isolated, they have no sustainable livelihood and are still denied access to many basic services, including health care.

19. The correlation between poverty and the risk of HIV infection is well-recognised and occurs at many different levels. Those living in poverty are less likely to have access to education, health care and other social resources. Many factors linked to poverty and deprivation of identity make them more vulnerable to sexual exploitation, or to become victims of trafficking in women and children. It may be difficult for people living in poverty to afford condoms or to insist upon their use. Moreover, the absence of hope is often associated with poverty deprive individuals of the psychological and emotional resources to protect themselves and others against HIV infection.

20. Because so many indigenous peoples are economically disadvantaged, it is important to appreciate the nexus between poverty and increased vulnerability to HIV. An understanding of

this connection needs to inform HIV policies and programmes for indigenous communities, since the issues involved transcend concerns about health alone and go to fundamental questions about indigenous status and the relationship between indigenous peoples and the larger communities within which they live.

***(c) Geographical Isolation***

21. As with any community living in a remote area, indigenous communities that are geographically isolated from major urban centres suffer particular forms of disadvantage that increase their vulnerability to HIV infection. Limited access to schooling results in lower levels of literacy and increased vulnerability to HIV. Public health campaigns, including HIV prevention, may not reach geographically isolated communities, and if they do, may have less relevance or practical application. Access to condoms may be difficult and expensive. Social problems in some geographically remote indigenous communities, such as alcoholism, drug use and domestic violence, may increase the risk of HIV transmission.

22. Access to health care is also a particular problem for all geographically isolated communities. Health facilities, if they are accessible at all, may be many hours away and may offer a limited range of services. Opportunities to obtain free or low-cost health care are more limited than in urban centres. Specialised HIV diagnosis, counselling and treatment is unavailable in most geographically remote areas, and concerns about confidentiality abound in small communities. For this reason, people in remote communities may be less likely to

acknowledge their risk of HIV infection and, in the absence of readily available HIV treatments, have little incentive to know their HIV status.

***(d) Different demographics – the disproportionate impact on young people***

23. The demographics of many indigenous populations differ from the demographics of the general population in the countries in which they live. Many developed countries are facing issues associated with increased longevity and an ageing population. The combination of increased morbidity and mortality, shorter life-spans and recent improvements in health and education for many indigenous people has meant that the majority of people in many of these populations are young people. Young indigenous people face particular issues of partial integration with mainstream society, disconnection from their traditional culture and dislocation from land.

24. HIV, sexual and reproductive health programmes need to be able to target these young people with acceptable and appropriate messages and support. This is complicated by their multiple identities as indigenous young people and as members of broader societies. Some cultural practices that put young people at increased risk also need to be addressed, some issues are difficult to speak out and discuss.-

***(e) The Consequences of Marginalization***

25. While not all indigenous cultures are minority cultures in the country in which they live, most of them are, and the consciousness of being marginalized from mainstream social, political and economic culture is a feature of much indigenous experience. Some indigenous communities choose to live separately or in voluntary isolation from the mainstream, but others are excluded by reason of their different traditions and culture. In either case, there is a sense of 'otherness' attaching to indigenous status and the risk of stigmatization within the broader community.

26. In the context of the HIV epidemic, it is now well accepted that marginalized groups within any society face a heightened vulnerability to HIV. This can be attributed to a range of factors. People already marginalized are more difficult to reach with HIV prevention messages and may be disempowered from taking steps, individually or communally, to protect themselves and others. If they already suffer stigma, they are less likely to acknowledge the risk of HIV infection and thereby expose themselves to further discrimination. Feelings of exclusion and an inability to exert control over one's own life are critical obstacles to HIV prevention.

27. Even within indigenous communities, there are groups who are more marginalized than others. As in many communities, indigenous or otherwise, the position of women and children may mean that they are especially vulnerable to exploitation and, in turn, to the risk of HIV infection. Marginalization may therefore be relevant at more than one level when considering HIV risks.

28. Marginalization of indigenous peoples has resulted in reduced access to essential health and welfare systems, to employment, to voluntary HIV counselling and testing services, sexual health services, ante-natal care including prevention of mother to child transmission (PMTCT), drug and alcohol services and HIV treatment care and support services. These services form the foundation of successful HIV programmes and whilst there are specific examples in some communities of attempts to tailor these services to the needs of indigenous peoples, these are not widespread enough to ensure the coverage required to produce desired HIV and health outcomes.

29. On the other hand, marginalization need not always have a negative impact on a community's capacity to respond effectively to the epidemic. An indigenous community may be marginalized from the mainstream and yet despite this, sometimes, as part of efforts of identity rebuilding, they try to maintain traditional sustainable way of life while coping with new challenges including HIV and AIDS. In this way, identification as indigenous can sometimes be empowering rather than the opposite, and it should not automatically be assumed that greater integration of a marginalized culture into the mainstream will necessarily enhance the capacity of that community to respond to HIV.

*(f) Different Understandings of Health and Medicine*

30. The international response to the HIV epidemic to date has been driven to a large extent by doctors and public health practitioners whose training, experience and understanding has come

from western medicine. Emphasis has been placed on ascertaining levels of HIV infection, reaching perceived 'at risk' populations with prevention programmes and expanding access to antiretroviral therapies and other forms of treatment.

31. For many indigenous communities however, the western medical tradition has no resonance. Such communities may have radically different understandings of disease and its spread, based on deeply-held spiritual or traditional beliefs. Scientific explanations of HIV infection and transmission may not be easily reconciled with traditional conceptions of disease in these communities. Even where traditional cultural practices may contribute directly to the spread of HIV, change is unlikely to occur just because western science dictates that it should.

32. Traditional healers play a centrally important role in many indigenous communities and shape their understanding about health and wellness. Often, wellness is understood to be much more than the absence of disease and may be inseparable from spiritual and religious dimensions. The community's faith in the healing power of traditional medicine may mean that traditional healers command a trust and respect far greater than that given to any doctor or health worker.

33. The different constructions of health and healing that exist in a large number of indigenous communities mean that many current HIV strategies are simply inappropriate for these communities, and that interventions developed within the western medical model are likely to fail. Different sources of trust and understanding within indigenous communities may need to

be recognised, including the role of traditional healers and other spiritual leaders. If appropriate partnerships can be created to develop HIV prevention and care programmes that draw upon the cultural understanding of traditional healers and spiritual leaders and the respect they command within their communities, these people can be important forces for change to reduce the impact of HIV on indigenous communities.

34. It is more common for indigenous communities to take a ‘whole of health/whole of life’ approach to dealing with health issues. In mainstream societies, health programmes are often vertical in nature, for example, dealing with HIV or heart health or diabetes. Indigenous knowledge and traditions favour dealing with people and communities in a more holistic way and this approach is often in conflict with the single disease or health issue model. Many indigenous communities are facing a wide range of health and wellbeing challenges and are searching for ways to incorporate a response to HIV into existing initiatives and programmes rather than deal with HIV as a single issue.

***(g) Low Levels of Participation in Political and Policy-Making Processes***

35. Whether as a result of history, cultural tradition, size or otherwise, few indigenous communities have strong representation in their national political institutions. While attempts have been made more recently in some countries to ensure indigenous participation in the policy-making process, at least in relation to issues concerning them, the more common

experience of indigenous peoples is that they lack a significant political voice in the country in which they live.

36. When it comes to the formulation of effective HIV strategies, the low level of political participation by indigenous peoples is a serious impediment. Because the spread of HIV in any community involves complex questions of culture, sexuality and social relations, and because indigenous cultures, by definition, are different from prevailing or mainstream cultures, the development of strategies to reduce the impact of HIV on indigenous populations requires real and active engagement with those communities. Just as the contribution and involvement of people living with HIV has been central to an understanding of the epidemic, and for the capacity to respond effectively, so too will the involvement of indigenous peoples in the policy-making process be essential to understand how and why the HIV epidemic is affecting indigenous peoples, and what can be done to bring about change.

37. The political invisibility of many indigenous communities however, presents a particular challenge in this regard. As long as indigenous communities remain outside the policy-making process, there is always a risk that they will be overlooked in HIV policies and programmes or that interventions will fail because they are not grounded in an understanding of indigenous culture and beliefs. The implementation of culturally-sensitive and appropriate HIV strategies for indigenous peoples can only be achieved if conscious efforts are made to draw indigenous communities into the policy-making process.

*(h) An increase in the burden of care that already exists in indigenous communities*

38. Because of poor levels of general health within many indigenous communities, many already bear a disproportionately high burden in terms of caring for family members and others who are sick. This burden is particularly high in remote communities with limited access to mainstream or community health care facilities and associated services such as home care. In these communities, the burden of caring of those who are ill falls upon relatives and other members of the community who may struggle to accommodate these demands due to their own poor health or socio-economic disadvantage.

39. Communities whose resources for care are already stretched by the burden of poor health are ill-equipped to deal with the further strain placed on them by HIV. This compromises not only the quality of care available to those with HIV but also the capacity of the community to embrace and act upon the need for effective HIV prevention measures. The response to the HIV epidemic is more likely to be one of helplessness rather than a resolve to take steps to avoid HIV infection.

**V. Leadership and advocacy actions the Permanent Forum could consider to reduce the impact of HIV on indigenous communities**

*a) Engage with the global movement towards universal access to HIV prevention and care*

40. The decisions of the United Nations General Assembly 2005 World Summit, the G8 Summit and the World Health Assembly to call for universal access to HIV prevention, treatment and care present an opportunity for the Forum to work with United Nations organizations and international aid agencies to ensure that indigenous issues are considered in the strategies and action plans that support these initiatives. Indigenous issues cut across all aspects of HIV prevention and care. Universal access targets will not be met if the implementing agencies are unable to deal effectively with the significant development issues facing many indigenous populations.

**The Forum currently receives regular reports from UN agencies. The Forum could require that future reports include coverage of progress against these universal access targets for indigenous communities**

41. This should not be a passive role for the Forum though. The outcomes will be more effective if the Forum and its members can find ways to work in partnership with these agencies and with others to assist in overcoming the significant barriers to access that exist in many communities and nations.

***b) Participate in the development of models of HIV intervention that acknowledge the social and economic factors that affect indigenous populations***

**42. Models of HIV prevention and care that have proven successful in non-indigenous communities need significant modification if they are to be relevant to and successful within indigenous peoples.** - The Forum and its members are well-placed to work in partnership with UN agencies, donors, regional and national HIV coordinating bodies to ensure that policies and programmes are adapted to the needs of particular indigenous peoples. -

**The production of a set of resources highlighting effective partnerships and successful HIV interventions in indigenous communities would assist external agencies to better tailor their programmes**

**43. Because so many of the factors that make indigenous communities particularly vulnerable to HIV relate not to health status but to their subordinate social, economic and political status within the broader societies in which they live, any policies on HIV in indigenous communities need to be seen in this context.** Efforts to encourage voluntary HIV testing and acknowledgment of HIV risks, for example, are unlikely to succeed if steps are not taken at the same time to protect already stigmatized indigenous populations from further discrimination. HIV care and treatment for indigenous people with HIV cannot be provided effectively where general health care is already unaffordable or inaccessible due to geographic isolation. Some indigenous peoples who face increased HIV risks because they have no means of support except sex work –or are vulnerable to human trafficking , cannot do anything in the face of those risks unless they are assisted in achieving a greater measure of economic self-sufficiency.

44. Addressing these broader social and economic determinants of vulnerability to HIV is a large task. Deep-rooted imbalances of this kind cannot be remedied easily or quickly, if at all. **Nonetheless, in formulating HIV policies for vulnerable communities such as indigenous peoples, it is important to acknowledge the social and economic realities of the lives of those people. Poverty alleviation, literacy education and legal advocacy services may assist in addressing HIV risks just as much as targeted public health education programmes. An integrated approach, that situates HIV policy in this broader context, is important to avoid the pitfall of seeing HIV as a stand-alone policy issue.**

*c) Advocate for the availability of better data and information to drive HIV policy and planning in indigenous communities*

45. The lack of accurate data and information to assist in HIV policy and planning for indigenous communities is a significant impediment to effective outcomes. While some jurisdictions have resisted the inclusion of ethnicity information in HIV surveillance programmes, fearing that this would increase the stigma and discrimination experienced by indigenous populations, the absence of data makes planning and resource allocation extremely difficult.

**The Forum could call for the development of a guidance paper by an appropriate UN agency to help surveillance system planners and policy-makers to safely include the**

**collection and reporting of ethnicity information in their second generation surveillance systems.**

46. Surveillance data is only one small part of the picture. The availability of social research data examining the particular context of risk in communities and the relative effectiveness of a range of HIV interventions is also a crucial part of the planning process. This appears to be lacking in many communities. **Further research on HIV in indigenous communities, if properly focused, could assist in the implementation of appropriate and effective policies.** Epidemiological data showing levels of infection and modes of HIV transmission can help to ensure that indigenous peoples –are not overlooked in HIV planning and resource allocation, and can assist in directing efforts to where they will have maximum impact. Research of this kind can also enhance understanding of what behaviours and environments place indigenous populations most at risk so that responses can be designed accordingly.

47. The possible harmful consequences of HIV research on indigenous populations must also be kept firmly in mind. Research in this area has to be approached with care. **Participatory research models, involving research collaboration with indigenous communities and strict adherence to the principle of free, prior and informed consent, can help to ensure that research in this area does not cause unintended harm and end up being contrary to the interests of indigenous peoples.**

**The Forum or its members could play a role in adapting and disseminating existing good practice documents that set out guiding principles for conducting research with, on and for indigenous communities.**

*d) Assist in the development of strategies based on an understanding of indigenous culture, practices and beliefs*

48. All communities have their own values and practices that must be understood in order to find effective ways of reducing the impact of the HIV epidemic. The values and practices of indigenous communities may be less well understood than others, because they are usually separate from the mainstream and may have particular traditions that are unique to them. These may range from different beliefs about health and disease, and different values governing relationships within families, to different sources of trust within the community and particular meanings given to the roles of traditional healers or other spiritual leaders.

49. Given the differences that may exist between indigenous beliefs and ways of living and those of other communities, it is evident that effective HIV policies for indigenous peoples must be based on an understanding of the culture, practices and beliefs of each indigenous community. - However, the difficult process requires at the outset an appreciation of what cultural factors may underpin particular forms of behaviour that place indigenous peoples at risk of HIV. **Only then can culturally-appropriate strategies for achieving change be developed within those communities.**

**The Forum and its members are in a good position to advocate for the development of training programmes and resources that assist HIV policy-makers and programme designers to take better account of these issues.**

*e) Foster indigenous community participation and informed consent in policy development*

50. No effort to disseminating information on HIV and related prevention programmes involving sex, sexuality or family relationships within a community will be successful unless the individual members of that community decide themselves that information and HIV prevention are necessary. This emphasises the fact that the principle of free and informed consent by indigenous peoples to interventions affecting them is not just rhetoric in this context. Rather, it is fundamental to the success of HIV policies and programmes for indigenous peoples. -

**51. For this goal to be achieved there must be active participation by and engagement with indigenous communities as a central part of the policy response. This is important not only for the development of policies grounded in an understanding of the cultural context within each community but also to ensure that the members of the community involved accept that HIV policy measures affecting them are necessary and appropriate and are committed to supporting them.**

**51. Mechanisms for achieving a genuinely participatory process may vary greatly between different indigenous communities and may need to be tailored to accommodate ethnic, cultural and linguistic difference. Tensions between individual and communal interests and within traditional community hierarchies may need to be recognised and dealt with. External policy-makers may still have an important role in this regard, and in facilitating and supporting the implementation of HIV policies within indigenous communities. However, the relationship needs to be one of partnership and collaboration, extending beyond mere ‘consultation’, notwithstanding the power imbalances that may exist between indigenous populations and the societies within which they live.**

**The Forum and its members have ample experience in fighting for meaningful participation of indigenous communities in all areas of policy and planning. They could bring this experience to the issue of HIV and provide leadership by setting and promoting a set of standards that agencies, donors and jurisdictions could use to improve their performance in this area.**

## **VI. Conclusion**

**53. To conclude on a positive note, it needs to be said that identification with a minority culture does not always have to be a disadvantage in this context. Any strong cultural identity can be a source of pride, and can provide a powerful motivation for those who identify with that culture to take steps to protect the welfare of their community. There are certainly**

**examples in the response to HIV where cultural minorities have been able to mobilize their communities to change behaviour that leads to the spread of HIV, by drawing upon a shared sense of purpose and a common wish for their community to live and thrive.**

**54. In developing HIV policy responses for indigenous peoples, the potential for identification with indigenous status to be used as a positive force in this way should not be overlooked. Even in communities suffering the effects of cultural dislocation and fragmentation, a wish to preserve indigenous culture and identity can still emerge as a force for change, as long as responses of this kind are nurtured and supported within the broader policy framework.**

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## **Appendix 1**

### **Summary of available surveillance and case-reporting data**

The data available on HIV and AIDS in indigenous communities are very sparse. Only a few countries and states within countries with significant indigenous communities have been collecting passive and active surveillance data. The available data is presented below. Many of the figures quoted refer to very small populations and the percentages can change dramatically with the inclusion of a single extra case. This makes any analysis of trends very difficult.

*Terminology: Each report refers to Indigenous peoples using different terminology. In each case the terminology of the report has been used. No offence to Indigenous peoples is intended in quoting these terms.*

### **Australia**

#### **The Australian 2005 Annual Surveillance Report<sup>1</sup>:**

- Per capita rates of HIV infection in the Indigenous and non-Indigenous populations are similar and both rates declined in the period 1995 – 1999.

- The rate of HIV diagnosis gradually increased from 4.0 per 100 000 in 2000 to 4.7 per 100 000 in 2004 for the non-Indigenous population
  
- In the Indigenous population the rate of HIV diagnosis increased from 3.7 in 100 000 to 5.2 per 100 000 from 2000 – 2004
  
- The rate of AIDS diagnosis in the Indigenous population rose from 1.5 per 100 000 in 2000 to 3.6 in 100 000 in 2004. (The corresponding rate for the non-Indigenous population declined to 0.8 per 100 000 in 2004).
  
- The main differences between the patterns of infections and risk in Indigenous versus non-Indigenous population are:
  - A higher proportion of Indigenous HIV infections are attributed to heterosexual sex than non-Indigenous HIV infections (36% for indigenous, 19% for non-Indigenous)
  - A higher proportion are attributed to injecting drug use (20% for Indigenous, 3% for non-Indigenous)
  - A higher proportion were among women (33% of Indigenous cases versus 10% of non-indigenous cases).

## **Canada**

### **HIV and AIDS in Canada: Surveillance Report to 30 June 2004<sup>ii</sup>:**

- Of the AIDS diagnoses prior to 1994, 86.4% were among White Canadians, 8.3% among Black Canadians and 1.3% among Aboriginal Canadians.
- Of the total AIDS diagnoses to 2003, 53.8% are among White Canadians, 20.7% among Black Canadians and 14.4% among Aboriginal Canadians.
- The proportion of Aboriginal Canadians among people diagnosed with HIV has remained relatively steady since 1998 at around 20%, whilst the proportion of Black Canadians among people diagnosed with HIV has increased from 5.3% in 1998 to 14.4% in 2004. (for those provinces/territories that submitted ethnicity data).

### **Trends of HIV risk and infection among Aboriginal Peoples in Canada<sup>iii</sup>:**

- Aboriginal peoples are over-represented in the HIV epidemic in Canada
- Aboriginal peoples make up a growing percentage of positive HIV reports and reported AIDS cases
- Injecting drug use continues to be a key mode of transmission in the Aboriginal community

- HIV has a significant impact on Aboriginal women – the national rate of HIV among pregnant women in Canada is estimated at 30 to 40 per 100 000 whilst one on-going British Columbia study has revealed a rate of 310 per 100 000 among Aboriginal pregnant women (10 times greater)
- Aboriginal peoples are being infected with HIV at a younger age compared to non-Aboriginal persons
- There is an increasing number of Aboriginal Peoples among newly-diagnosed people with HIV.

It is important to note that only 29.4% of the 12 600 positive HIV tests reported in Canada between 1998 and 2003 contained any information about ethnicity.

## **New Zealand**

### **HIV/AIDS in New Zealand 2004<sup>iv</sup>:**

A total of 1212 people have been diagnosed with HIV since 1996. 5.7 % of the men diagnosed and 0.7% of the women diagnosed have identified as Maori.

## **United States of America**

### **CDC HIV/AIDS Fact Sheet:<sup>v</sup>**

There are no HIV data presented. Several states with significant Indigenous populations have only recently passed laws to require HIV surveillance.

AIDS data show:

- Survival rates are lower for Indigenous people with AIDS
  
- In 2004, the estimated AIDS diagnosis rate among American Indians and Alaska Native adults and adolescents was 10.4 per 100 000 compared with 75.4 among African Americans, 26.8 among Hispanic Americans and 7.2 for white Americans.
  
- A risk factor analysis for HIV diagnoses among American Indians and Alaska Natives from 2000 – 2003 shows:
  - For males: 61% from male to male sex, 11% from males to male sex and injecting drug use, 15% from injecting drug use alone and 12 % from heterosexual sex
  - For females, 69% from heterosexual sex, 29% from injecting drug use.

**CAPS Fact Sheet: What are of American Indians and Alaskan Natives' HIV Prevention Needs? <sup>vi</sup>**

- Data are difficult to interpret as American Indians and Alaskan Natives are often wrongly classified because of assumptions about skin colour, name or residence or because people being tested sometimes give false ethnicity information, fearing stigma and discrimination.
- HIV risk in American Indian and Alaskan Native communities is compounded by higher levels of poverty, unemployment, substance use, sexually transmitted infections and violence.

### **Central & South America:**

“Indigenous communities and some ethnic communities tend to have higher rates of HIV infection than the general population. In Honduras in 1999, the HIV prevalence rate was six times higher among the Garifuna communities on the Atlantic Coast than it was among the general population. Also in Honduras the Miskito Indigenous community has been strongly impacted by the HIV epidemic. A seroprevalence study conducted at the end of the 1990’s among the Kuna people in Panama indicated an HIV prevalence higher than the national average. The case among Indigenous populations is similar in Canada. In Suriname, according to a study conducted in 1997, 17% of all cases of HIV/AIDS in the country occurred among the ethnic group known as “Maroon”, even though the Maroon account for only 10% of the population.”<sup>vii</sup>

### **Appendix 2**

## Reading and Resources used in the preparation of this report

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[www.linkup-connexion.ca/catalog](http://www.linkup-connexion.ca/catalog)

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Aboriginal and Torres Strait Islander Cultural Awareness Package: A Training Manual for AFAO Membership, *Australian Federation of AIDS Organisations*, [www.afao.org.au](http://www.afao.org.au)

Asian Americans and Pacific Islanders and HIV/AIDS, *Health Brief, Asian and Pacific Islander American Health Forum*, March 2003, [www.apiahf.org](http://www.apiahf.org)

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An Overview of Models for Community Based Aboriginal HIV/AIDS Research, *Healing Our Spirit BC Aboriginal HIV/AIDS Society*, August 2002, [www.healingourspirit.org](http://www.healingourspirit.org)

Report of the Workshop on Data Collection and Disaggregation for Indigenous Peoples, *United Nations Permanent Forum on Indigenous Issues*, Third Session, 10-21 May 2004, [www.un.org/esa/socdev/unpfii/](http://www.un.org/esa/socdev/unpfii/)

Report of the International Workshop on Methodologies regarding Free, Prior and Informed Consent and Indigenous Peoples, *United Nations Permanent Forum on Indigenous Issues*, Fourth Session, 16-27 May 2005, [www.un.org/esa/socdev/unpfii/](http://www.un.org/esa/socdev/unpfii/)

The Rights of Indigenous Peoples, *Fact Sheet no.9, Office of the United Nations High Commissioner for Human Rights*

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Gary Meyerhoff (2000): Injecting drug use in urban indigenous communities: A literature review with a particular focus on the Darwin area. Danila Dilba Medical Service, Darwin, Australia

Sellman JD, Huriwai TT, Ram RS, Deering DE (1997): Cultural linkage: treating Maori with alcohol and drug problems in dedicated Maori treatment programs. *Subst. Use Misuse*; 32(4): 415-24.

Patterson KM, Holman CD, English DR, Hulse GK, Unwin E. (1999): First-time hospital admissions with illicit drug problems in indigenous and non-indigenous Western Australians: an application of record linkage to public health surveillance. *Aust. N. Z. J Public Health*; 23(5): 460-3.

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<sup>i</sup> HIV/AIDS, Viral Hepatitis and Sexually Transmissible Infections in Australia: Annual Surveillance Report 2005, National Centre for HIV Epidemiology & Clinical Research, UNSW, 2005

<sup>ii</sup> HIV and AIDS in Canada: Surveillance Report to 30 June 2004, Public Health Agency of Canada, November 2004

<sup>iii</sup> HIV/AIDS Epi Notes: Understanding the HIV/AIDS Epidemic among Aboriginal Peoples in Canada: the Community at a Glance, <http://www.phac-aspc.gc.ca/publicat/epiu-ae/pi-note/index.html>

<sup>iv</sup> AIDS New Zealand, Issue 55 – February 2005, University of Otago

<sup>v</sup> CDC HIV/AIDS Fact Sheet: HIV/AIDS among American Indians and Alaska Natives, CDC, July 2005

<sup>vi</sup> CAPS Fact Sheet: What are of American Indians and Alaskan Natives' HIV Prevention Needs?, UCSF, January 2002,

<sup>vii</sup> From the Regional HIV/STI Plan for the Health Sector 2006 – 2015, WHO Pan American Health Organization 2005