Indigenous Peoples' Rights to Health:

Where are we and where are we going?

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1. Introduction

Indigenous peoples[1] represent an astonishing diversity of cultures, religions and languages and a priceless reservoir of knowledge and skills. But the future for many of these groups is bleak. Most live in remote and inaccessible areas with little access to health care, and suffer the same, or worse, isolation from services as do many rural communities. Commercial pressures and environmental degradation result in the continued loss of the land on which their livelihood and traditional way of life depend. Ironically, exploitation of the land of indigenous peoples is often due to high international demand for the very resources which indigenous communities themselves have carefully managed and protected for centuries- including medicinal plants, forest products, timber and natural mineral resources. (Barton 1994; King and Tempesta 1994; Calle 1996; King, Cartson et al. 1996; Merson 2000) At the extreme, indigenous peoples suffer systematic repression and deprivation, to the extent that their very survival is threatened. For most, life is a constant struggle in the face of poverty, ill health and social disintegration.

In 1994, the United Nations declared an International Decade of the World's Indigenous Peoples, with the objective of "strengthening international cooperation for the solution of problems faced by indigenous peoples in such areas as human rights, the environment,

[1] Indigenous Peoples are 'a non-dominant group of people with a shared history, language and culture residing in a common geographical area. Indigenous peoples are…non-state people not participating in an industrial mode of production and are thus vulnerable in relation to modernization and the state.' (Kempe 1997 p.6)

development, education and health."[2] In 2004, the decade ended with little achievement. In October 2004, the United Nations Human Rights Commission released a preliminary review of the decade. Its conclusions are shown in the box below.

> ***Despite the important institutional developments that have taken place in the framework of the Decade…indigenous peoples in many countries continue to be among the poorest and most marginalized….the adoption of a declaration on the rights of indigenous peoples, one of the main objectives of the Decade, has not been achieved. (UNHCR 2004)***

A few weeks later, as the decade drew to a close, the Third Committee (Social, Humanitarian and Cultural) of the UN General Assembly met to discuss indigenous peoples. Reflecting on the lack of achievement of the first decade, they recommended that the General Assembly proclaim a Second International Decade of the World's Indigenous Peoples beginning on 1 January 2005.

2. Where are we now? The Policy Context

Addressing the issue of indigenous peoples' health has to be part of the wider development agenda. This is currently dominated by the attempt to achieve the "Millennium Development Goals" and the emergence of human rights as a key issue.

2.1 The Millennium Development Goals

As the 21st Century opened, the international community took stock of progress in development following a decade of summits and declarations setting a new agenda following the end of the cold war. In September 2000 the Millennium Declaration was signed by 189 countries setting eight Millennium Development Goals (MDGs). The MDGs have become the international focus of development programmes. Of the eight goals, three are directly aimed at health with 12 targets to measure progress in reducing child mortality, improving maternal health and combating HIV/AIDS, malaria and other diseases.[3]

[2] http://www.unhchr.ch/indigenous/decade.htm
[3] The targets are based on 1990 baseline figures

Indigenous peoples, many of them living in remote and inaccessible areas are symptomatic of the failure of the MDG framework to address the issue of equity within countries as well as between them with ministries of health focusing on the 'big battalions of the vulnerable, in geographically more accessible zones.'[4]

In Oct 2004, the Inter-Agency Support Group on Indigenous Issues issued a statement declaring that "as the 2005 review of the implementation of the MDGs nears, it appears from the available evidence that indigenous and tribal peoples are lagging behind other parts of the population in the achievement of the goals in most, if not all, countries in which they live, and indigenous and tribal women commonly face additional gender-based disadvantages and discrimination." (Inter-Agency Support Group for the UN Permanent Forum on Indigenous Issues 2004) If the health needs of indigenous peoples are to be met, there needs to be a far more inclusive approach including the provision of high quality and culturally appropriate health services controlled by indigenous communities.

2.2 Human Rights, Health and Indigenous Peoples

Human rights have re-emerged alongside health needs at the centre of the development debate. The right to an adequate standard of living for the health and well-being of the individual and their family and to share in scientific advancement and its benefits is enshrined in the Universal Declaration of Human Rights (United Nations 1948), and the International Covenant on Economic, Cultural and Social Rights states that everyone has the right to enjoy the highest attainable standard of physical and mental health. Attempts to have a comprehensive international declaration on the rights of indigenous peoples as a finale to the international Decade, first drafted in 1994, have all failed. Articles 23 and 24 of the draft declaration set indigenous peoples' rights to traditional medicine and health practices and the protection of vital medicinal plants, animals and minerals, their right to determine and develop and administer health programmes affecting them and to have access, without any

[4] The evidence suggests that 73 countries are far behind in meeting the MDGs for infant mortality, and 66 are far behind for meeting the MDGs for child mortality. The disease burden can be brought down in line with the MDGs only if there is a concerted, global strategy of increasing the access of the world's poor to essential health services. WHO Millennium Development Goals www.who.int/mdg/en Accessed 23 August 2004

discrimination, to all medicinal institutions, health services and medical care (United Nations High Commissioner for Human Rights 1994)

2.3 Land Rights and Indigenous Peoples: Dispossession, Culture and Health

It is "almost impossible to exaggerate the emotional, spiritual, and economic importance of land to indigenous communities," writes John Hemming in his account of Brazils Indian Communities in the twentieth century (Hemming 2003, p 345). In both industrialized and developing countries, dispossession from ancestral lands and the consequent disruption of community and culture have been the key factors in marginalizing and impoverishing indigenous peoples and lie at the root of their poor health. Increasingly in the industrialized world efforts are being made to address the issue (Bourne 2003) but more needs to be done.

'A few years ago a Cambodian mining company began excavating gold on land belonging to our village. Neither the company nor the district authorities had asked permission from the village elders. The mines were closely guarded day and night. We were strictly forbidden from entering the land on which the mining was taking place. Prior to the arrival of the miners we had seen little sickness in our village. Shortly after the mining started, villagers began to suffer from a range of health problems, which included diarrhea, fever, headaches and coughing and vomiting with blood. The sickness mainly affected children but a small number of adults also were affected. 25-30 people became ill, of which 13 eventually died. We feared that the village spirit had become angry, as outsiders were mining land, and this has been a taboo for a long time.' - Dian Phoeuk, Pao Village Elder, Taveng Kronm Commune, Rattanakiri Province, Cambodia. Source: (Bristow, Stephens et al. 2003)

From the San in Botswana to Yora in Peru, from the Tampoen in Cambodia to the Jarawa of the Andaman Islands, indigenous peoples in the developing world face increasing threats to their lands, culture and livelihoods from governments and corporations seeking to exploit natural resources and from other marginalized groups seeking access to land. For the future

health and wellbeing of indigenous peoples, the right to set the terms on which they wish to engage with the modern state and economy is crucial.

3. Where are we now? Health of Indigenous Peoples

3.1 Health Status of Indigenous Peoples

The health experience of most indigenous peoples is not well documented. WHO reports that there is little reliable information on indigenous peoples' health. This information vacuum impedes a broad national and global understanding of the range and extent of health issues affecting indigenous peoples everywhere. Despite the data gaps, some consistent patterns emerge that demonstrate that the health of indigenous peoples is significantly poorer than other groups within their societies, with life expectancy shorter and infant mortality rates up to three times greater (Basu 1994; Hudson 1999; Gold, et al. 2000; Allesandri, Chambers et al. 2001; Escobar, Coimbra et al. 2001; Hetzel 2001).

The weak health and demographic information systems in most developing countries do not permit accurate, systematic and routine measurements and monitoring of demographic indicators or health trends and status of different population groups. Data and information on populations in remote areas or informal settlements- where marginalized populations are often concentrated- are particularly scant. (World Health Organization 2002)

Many communities are overwhelmingly affected by communicable disease and nutritional deficiencies, but are also at risk of higher rates of injury (Saborio, Gonzalez et al. 1998; Stevenson, Wallace et al. 1998; Wheatley and Wheatley 2000). Loss of lands and livelihoods is reducing food security and malnutrition and is an increasing factor that underlies the ill health of indigenous peoples- threatened food sources sometimes means the loss of an entire way of life. In many cases, indigenous communities are dependent on rapidly deteriorating ecosystems: for example, indigenous fishing communities are increasingly at risk from contamination of their major food source (Van Oostdam, Gilman et al. 1999; Gold, Geater et

al. 2000; Merson 2000; Powell and Stewart 2001; Trotti 2001; Louw, Regnier et al. 2002). In addition, environmental quality is frequently low in areas where indigenous peoples reside and contributes to undermining health and well-being. At best the health situation of indigenous peoples' mirrors that of the very poorest in the world, but is made worse by their marginalization and vulnerable small populations. At its most extreme, the health experience of indigenous peoples sometimes has critical impacts on their demographic viability as a people. The Box below describes the impact of an epidemic on the Wa community in Burma. Although the impact of this epidemic was not catastrophic it will clearly have an effect on the structure of the population in the future. In other places epidemics introduced from outside have diminished and sometimes wiped out whole group of peoples, cultures and languages (Joralemon 1982; Ubelaker 1992; Souza and Santos 2001).

'Five years ago, in the same season as now, when the green mountain rice just as high as your hands, Ye'an of our village first started to have diarrhea. Within several days, everybody in our village started to have diarrhoea, and people started dying. At first, the villagers still gave the dead person a ceremony and funeral. But as the number of deaths increased to six or eight each day, we did not have enough time to bury the dead people, not to mention giving them a proper funeral. No one thought of inviting doctors, or witch doctors. Everyone felt in danger, everyone was scared, and all people in the village had fled within seven or eight days. More than one month later, villagers began to return. My current family was established after that disease and my current wife also her family, her former husband and one child also dying of the disease.'

Ai'ong, 40+ year old man, Wa ethnic group, Nanpadi township, Bangkang special district, Wa state, Burma.

Source (Bristow, Stephens et al, 2003)

3.2 So how do Indigenous Peoples define their own health?

Many factors contribute to the health and well-being of indigenous peoples. An absence of illness is only part of the picture. Factors such as the ability to work, the availability of work and access

to food and water are important. But the individual is only one part of the story. Being in harmony with other people - family, neighbors and village- and with the environment, is crucial to indigenous peoples. Their concept of health is one of collective well-being with other humans and other species. In many ways the concept of health for indigenous peoples is a wider and more ecological concept than that defined by the World Health Organization.[5]

'Well-being means that my body and mind are happy and well and that I have a good appetite, that I eat and sleep well and have no problems in the family or in the village.'- ***Cham Heb, 20 years old mother, Tampoeun ethnic group, Prak Village, Samaki Commune, Rattanakiri Province, Cambodia.***

'I think that well-being in our house and home and also with our neighbors is when there is peace and happiness- and also when we love ourselves. It's like God says to us, you shouldn't only want your own wellbeing. You should also think of your neighbors. You have to think of your neighbors, whether they have enough food to eat, or maybe they're suffering. It is important to think of them. You have to share the happiness that you may have with your brother.'- ***Juana Tzoy Quinillo: 55 years old, Traditional Birth Attendant and Curer: Pachojob', K'iche' ethnic group, Santa Lucia la Reforma Municipality, Totonicapan Department, Guatemala.***

'Well-being is to live like other people and to fit in with them. Proper house, water and nice clean clothes would make me happy and is what I need to be well.'- ***Jamba, traditional leader, San ethnic group, Uzera, Tsumkwe West, Namibia.***

Well-being, for me is like the others have said, utz'ilal. It's when we're not fighting with our family. In the home. It also means peacefulness when we go to sleep.'- ***Irma Pu Tiu: Madre Vigilante, K'iche' ethnic group, Gualtux, Santa Lucia la Reforma Municipality, Totonicapan Department, Guatemala.***

Source: (Bristow, Stephens et al. 2003)

[5] Health "is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity." (Preamble to the Constitution of the World Health Organization as adopted by the International Health Conference, New York, 19-22 June, 1946; signed on 22 July 1946 by the representatives of 61 States (Official Records of the World Health Organization, no. 2, p. 100) and entered into force on 7 April 1948)

Knowledge and belief systems which link the spiritual closely with the environment can strongly influence well-being. Exploitation of indigenous lands, medicinal plants and forests has a profound effect not only the physical environment, but the fabric of indigenous society.

3.3 "Health" services for indigenous peoples

Indigenous Peoples often have sophisticated and well established systems of traditional medicine – with tried and trusted remedies developed over time (Crengle 2000; Hickman and Miller 2001; Fink 2002; Louw, Regnier et al. 2002). Very often their societies have highly prized ethnic medicines which become contested goods in international markets (Mail, McKay et al. 1989; Trotti 2001; Louw, Regnier et al. 2002; Kong, Goh et al. 2003). In many cases these systems have been fragmented over time, and undervalued in the context of western medicine (Janes 1999; Chang 2001; Cook 2001). However, not all health problems can be effectively addressed by indigenous healing systems – as indigenous healers themselves recognize. This is partly because many indigenous communities are now facing introduced diseases of which they have limited or no former experience. For example childhood illnesses that are a factor in high infant and under-five mortality – e.g. diarrhoea disease, acute respiratory disease are major problems for indigenous communities but are relatively recent introductions to the illness experience of many indigenous groups.

But when they need it, indigenous peoples do not have easy access to basic Western health care (Wilkinson, Ryan et al. 2001; Pal, Das et al. 2002; Simmons and Voyle 2003). Access is constrained by financial, geographic and cultural barriers. Indigenous peoples are low on governments' priority lists, especially when they live in remote areas where services are difficult and costly to provide. Where services are available, indigenous peoples are often reluctant or afraid to use them because staff can be insensitive, discriminatory and unfriendly (Escobar, Coimbra et al. 2001; Palafox, Buenconsejo-Lum et al. 2001). For many communities, health services are poorly resourced and access to emergency care, including emergency obstetric care, is only available at great distances. Many communities have little access to information regarding their rights and entitlement to health care. In addition to the cost of care borne by families to reach health services, lack of explicit information about health care charges can be a further barrier to use.

4. What are the solutions? A new Agenda

To improve the health of indigenous peoples further research and urgent action are needed internationally. Information has to be gathered locally to take into account the wide differences between indigenous peoples and their circumstances. Beliefs, practices and circumstances for the six communities whose experiences are recounted in Utz' Wach'il (Bristow 2003) range widely. Research undertaken by LSHTM in other communities confirms this and points to the need for more work to be undertaken by researchers in consultation with communities and with policy makers to ensure that appropriate policies and practices are developed. But there are also common elements which are evident.

In Ayacucho, Peru indigenous women reported that the birthing service provided by the Ministry was inappropriate by staff. Health Unlimited worked with indigenous women, traditional birth attendants and Ministry of Health personnel to design a culturally sensitive birthing Centre which combines traditional practices, including attendance by the TBA and family members, with access to emergency services if needed. (Bristow, Stephens et al. 2003)

Addressing the health problems has to be part of a wider development agenda and is a long-term process. The health of indigenous peoples, particularly small communities living in remote areas in developing countries, is increasingly threatened. Wider economic, social and political issues underlie the problems of poor health. Destruction of the environment through logging, mining and the construction of dams, increasing invasion of traditional lands by commercial farmers and pastoralists are destroying the land and livelihoods of indigenous peoples. Their small numbers and remoteness from the centres of power make it easy for them to be ignored by policy makers and service providers.

Poverty and marginalization combined with the effects of conflict underlie the stories of ill health amongst indigenous peoples. At the core of health policy has to be a commitment to empowering indigenous peoples to make their own decisions about the nature of health services they want. For indigenous peoples, health and wellbeing are intimately bound up with relationships between people in their communities and between people and the environment. Outsiders,

including government departments, national organizations and international agencies seeking to work with indigenous peoples, have to respect and work with traditional structures and practitioners.

Indigenous communities recognize the need for allopathic medicine to deal with certain conditions, particularly those that have been introduced from the outside and those for which there are not traditional remedies. But what these are and the nature of the services provided should be determined in consultation with communities and not imposed from outside.

The value of indigenous medical knowledge is also increasingly recognized. As well as seeking to integrate traditional and allopathic systems and knowledge in the services for indigenous peoples, traditional knowledge needs to be protected from exploitation by outside interests.

Urgent action is needed. The International Decade of Indigenous Peoples started in 1994. It took seven of the ten years for WHO to make recommendations for a global plan action. But very little has been achieved on the ground, and the threats to indigenous peoples are growing rather than diminishing. While global and national policies are needed, there is also a need for action now.

The UN Permanent Forum is now functioning, and could serve as a focal point for indigenous raising indigenous issues. But it needs to free itself from bureaucratic shackles and set up mechanisms which ensure that the voices of indigenous communities and organizations are heard. Space has to be made to enable the rich variety of voices, and particularly those most remote and most threatened, to be articulated to policy makers. In our Second Decade the Permanent Forum has a unique opportunity to facilitate this.

Declining health because of introduced disease and the threat of HIV/AIDS combined with loss of lands and livelihoods threaten the existence of many indigenous peoples. At the international level there needs to be a far stronger commitment of donors to ensuring that attention is given to the right to health of the poorest and most marginalized people and specifically indigenous peoples. The WHO proposals suggest that equity oriented development initiatives such as the Poverty Reduction Strategy Process (PRSP) and implementation of the United Nations Millennium Declaration should be used to meet the health needs of indigenous peoples. But there are grave concerns about the implementation of PRSPs in many countries and doubt about

the possibility of meeting the Millennium Development Goals; and it is clear that the needs of the most marginalized are not being addressed. International donors need to ensure that health needs of indigenous peoples are included in development plans for which international assistance is sought.

Millennium Development Goals related to Health

- ***Reduce by two thirds, between 1990 and 2015, the under-five mortality rate***
- ***Reduce by three quarters, between 1990 and 2015, the maternal mortality ratio***
- ***Have halted by 2015 and begun to reverse the spread of HIV/AIDS***
- ***Have halted by 2015 and begun to reverse the incidence of Malaria and other major diseases***

It is vital, too, that national governments should give equal weight to the special needs of indigenous peoples. There are common features, but the examples in this document illustrate a wide range of beliefs and actions about health which must be respected. Decisions on priorities and provision must be done within a participator framework which recognizes diversity of language, culture and organization. Diversity, small populations and remote location make it difficult for governments to reach indigenous communities; but NGOs and civil society, and particularly indigenous peoples organizations can play an important role in supporting the development of appropriate services linked to government provision.

Research has a vital role in informing policy and examining practice. We need to know far more about the ways in which indigenous peoples' concepts of health and well-being differ from those of more dominant groups within societies. We need to know far more about traditional medicine and its effectiveness. And where services are developed- do they improve peoples' health? Or their well-being? Action which is taken needs to be researched and evaluated. We also need the international research community to show how the lives and rights of indigenous peoples are affected by global and local changes, and to investigate whether and how they are additionally affected by global processes. We need the research community to work together with the NGO community to advocate for indigenous peoples' rights to health and well-being.

Finally and most important, we need researchers, governments and NGOs to work with indigenous peoples, communities and organizations to strengthen their voice to articulate what it is that they want and do not want from the outside, and what they need to ensure their health and well-being.