SECTION 1: LIVING WITH HIV
A DOCUMENT PREPARED BY GNP+

INTRODUCTION

Global Network of People Living with HIV (GNP+) is pleased to be cooperating and contributing to this resource kit for lawyers and advocates working on criminalisation of HIV exposure and or transmission cases. In partnership with AIDES, the Canadian HIV/AIDS Legal Network and Groupe sida Genève, GNP+ will work to continually provide or sign post the most up to date information to lawyers and advocates with the aim of reducing the harms arising from an uninformed and overly broad use of criminalisation in HIV exposure and transmission cases.

The mission of GNP+ is to improve the quality of life of all people living with HIV (PLHIV). Its work is based on shared principles that include a commitment to ensuring that the network is driven by constituency's needs, the understanding that HIV is a human rights issue and the commitment to promoting the meaningful involvement of people living with HIV at all levels of the HIV response.

In the early years of the epidemic, ignorance, prejudice and misinformation combined to create a negative perception of HIV and people living with HIV, resulting in a delay in effectively responding to the epidemic. Against this background, some governments sought to regulate transmission of the virus by applying criminal law and other punitive measures against people who transmitted or exposed others to the virus. 20 years on, there is no evidence to show that laws that explicitly regulate the sexual conduct of people living with HIV significantly impact on sexual conduct or moderate risk behaviours[1].

The Scope of this section of the tool kit

The section of the tool kit will give a perspective of the impact of HIV from the point of view of people living with the virus. It will look at the impact of treatment on the epidemic and on the quality of life of people infected. It will also explore social and personal aspects of living with HIV and how these are impacted upon by criminal and other punitive measures applied to HIV transmission and exposure.

1. HIV transmission and epidemiology

A historical perspective of HIV and AIDS

The earliest public account of Acquired immune deficiency syndrome (AIDS) is by the Atlanta based US Centres for Disease Control (CDC) in 1981. In its Weekly and Morbidity and Mortality Report of 5th June 1981, CDC reported the emergence of previously rare clusters of diseases such as *Pneumocystis carinii*, a type of pneumonia, and *Kaposi sarcoma*, a normally slow growing cancer (Barnet and Whiteside, 2006). Most of these cases were recorded in New York and San Francisco among young homosexual men. By 1982, the illnesses were being recorded in

[1] Z. Lazzarini and others, "Evaluating the impact of criminal laws on HIV risk behavior", Journal of Law, Medicine & Ethics, vol. 30 (summer 2002), pp. 247–249.

other parts of the world and among other definable groups including haemophiliacs, recipients of blood transfusions, injecting drug users as well as partners and children of those infected. By 1983, human immunodeficiency virus (HIV) had been identified as the virus attacking the body's immune system and causing AIDS. However, HIV does not always cause AIDS; many people live with the virus for several years before it begins to make a significant impact on the body.

HIV transmission

HIV can be contracted primarily by:

- Having unprotected sex (not using a condom when having sex) with a person who has HIV. All unprotected sex with someone who has HIV contains some risk, however, presence of other sexually transmitted diseases (STDs) can increase the risk of infection during sex;
- Sharing needles, syringes, rinse water, or other equipment during injecting drug use. HIV can also be transmitted by being "stuck" with an HIV-contaminated needle or other sharp object in any setting.
- HIV can be transmitted from mother to child during pregnancy, birth, or breast-feeding.
- Receiving blood transfusions, blood products, or organ/tissue transplants that are contaminated with HIV. This risk is extremely rare in countries where donated blood and body tissue are tested before transfusion.

In the context of criminalising HIV exposure or transmission, it is important to note that saliva has never been shown to transmit HIV.[2]

More information about the history of HIV and modes of transmission can also be found at, amongst other places:
http://www.cdc.gov/hiv/topics/basic/
http://www.avert.org/howcan.htm

Current epidemiological trends

Since the beginning of the epidemic, almost 60 million people have been infected with HIV and 25 million people have died of HIV-related causes. In 2008, some 33.4 million people living with HIV, 2.7 million new infections and 2 million AIDS-related deaths (UNAIDS, 2009). In 2008, the total number of children under 15 living with HIV was 2.1million.

Sub-Saharan Africa is the region most affected and is home to 67% of all people living with HIV worldwide and 91% of all new infections among children. In sub-Saharan Africa the epidemic has orphaned more than 14 million children. Women are disproportionately affected.

[2] Centers for Disease Control, "Contact with saliva, tears, or sweat has never been shown to result in transmission of HIV," (last reviewed and modified October 20, 2006) online at www.cdc.gov/hiv/resources/qa/qa37.htm.

Southern Africa is the epicentre of the epidemic with a number of countries recording adult HIV prevalence above 15%. HIV infection in Africa is primarily through heterosexual transmission.

In the **Caribbean**, heterosexual transmission, often linked to sex work, also accounts for the generalised HIV epidemics observed in a number of countries. Emerging evidence indicates that substantial transmission is also occurring among men who have sex with men. A 2006 study in Trinidad and Tobago found that 20.4% of men who have sex with men surveyed were infected with HIV. In Jamaica, another study found HIV prevalence of 31%.

In Asia, an estimated 4.7 million people were living with HIV in 2008. Asia, home to 60% of the world's population, is second only to sub-Saharan Africa in terms of people living with HIV (UNAIDS, 2009). India accounts for roughly half of Asia's HIV prevalence. The proportion of women living with HIV in the region rose from 19% in 2000 to 35% in 2008. Although Asia's epidemic has long been concentrated in specific populations, namely sex workers and their clients, men who have sex with men and injecting drug users, it is steadily expanding into lower-risk populations through transmission to the sexual partners of those most at risk.

In Eastern Europe and Central Asia, 1.5 million adults and children were estimated to be living with HIV in 2008 (UNAIDS, 2009). HIV prevalence in the region is on the rise particularly in the Ukraine and the Russian Federation. With an adult HIV prevalence of 1.6% in 2007, Ukraine has the highest prevalence in all of Europe. Injecting drug use remains the primary mode of HIV transmission in the region. With increasing transmission among the sexual partners of drug users, the epidemic is increasingly characterised by significant sexual transmission.

The epidemics in **North America, Western and Central Europe** are concentrated among key populations at higher risk, especially men who have sex with men, injecting drug users and immigrants (UNAIDS, 2009). In the United States of America for instance**,** African–Americans represent 12% of the population but accounted for 46% of HIV prevalence. In the high income countries of these regions, late diagnosis of HIV infection remains a challenge. AIDS-related deaths in **Latin America** were estimated at 77 000 in 2008 (UNAIDS, 2009).

More information on current epidemiological trends can also be found at, amongst other places:

http://www.who.int/hiv/data/2009_global_summary.gif
http://www.unaids.org/en/KnowledgeCentre/HIVData/GlobalReport/2008/

2. Living with HIV in 2010

The impact of an HIV positive diagnosis will be different depending on many variables including, where a person lives, the availability of treatment, availability of emotional and other support, one's state of health at the time of diagnosis and whether or not a positive result was expected. For most people, being diagnosed with HIV will be a significant event in their lives. The reactions to an HIV positive diagnosis will also vary widely from person to person.

However, commonly reported reactions include feeling numb, frightened, upset, tearful, and desperate and in some cases, people have reported feeling relief.

Impact of Treatment on Physical Wellbeing

> Arguably the most significant impact on the physical wellbeing of PLHIV has been the advent of anti-HIV medicines that maintain the functionality of the body's immune system. Unfortunately, these treatments, which can enable people living with HIV to have a good quality of life, are not available or affordable to the majority of people living with the virus. Prior to the availability of treatments, most people suffered rapid disease progression and died. Now, research shows that if people begin taking treatment before their immune system is significantly damaged, they are likely to have a normal lifespan[3]. Conversely, where PLHIV remain untreated, there is a risk of dying within approximately 10 years of being infected.[4]

Whilst availability of treatment has resulted in a notable decrease in HIV related deaths[5], according to the World Health Organization (WHO), only less than half of the people who need treatment have access to it. Treatment access is especially low in many developing countries. In recent years, significant resources have been directed towards achieving universal access to treatment for HIV as part of a wider objective to provide universal access to treatment, care and prevention by 2010[6].

It is important to note that, not everyone responds well to HIV medications. Some people will develop resistance to the medication which can limit its efficacy and also limit the treatment options that remain available to the person. Taking treatment when significant damage has already occurred to the immune system can also limit its impact. As well as availability and affordability, alcohol, drugs, instability and mental illness can also impact on people's ability to access treatment.

More information on the impact and availability of treatments can also be found at, amongst other places:

http://www.avert.org/universal-access.htm
http://www.who.int/hiv/mediacentre/news57/en/index.html
http://www.aidsmap.com/cms1000229.asp

The positive effects of treatment on the physical wellbeing of people living with HIV have resulted in impacts in other areas of people's lives.

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[3] Harrison KM et al. Life expectancy after HIV diagnosis based on national surveillance data from 25 states,United States. J. Acquired Immune Defic Syndr 53{1}:124-30, 2010
[4] UNAIDS. AIDS Epidemic update: December 2007 estimates the number of years that people living with HIV are expected to survive without treatment at between nine to eleven years.
[5] UNAIDS, 2008 Report on the Global AIDS Epidemic. Geneva 2008.
6 World Health Organization, 'Universal Access by 2010', accessed 24th June 2009. WHO/UNAIDS/UNICEF (2009), 'Towards Universal Access: Scaling up priority HIV/AIDS Interventions in the Health Sector'

Serodiscordant relationships

For example there is an increase in the number of HIV discordant couples.[7] Discordance in the context of HIV refers to sexual partnerships in which one partner is HIV positive and the other HIV negative. Having biological children, while avoiding HIV transmission to the HIV – negative partner, has been found to be a major concern amongst serodiscordant couples.[8] In general, the conflict or tension relates to, amongst other things, fear of infecting the HIV-negative partner and strained relations at the time of first disclosure.

Improved physical health also has an impact on sexual reproductive health and rights.

Sexual Reproductive Health and Rights

> With treatment and care becoming increasingly available, PLHIV are regaining their health, living longer, fulfilling lives, and planning for their futures. This includes decisions about sex, sexuality and the possibility of starting or expanding families[9].

In a working group statement produced following the Living 2008 summit (a gathering of people living with HIV from all over the World at the World AIDS Conference of 2008), PLHIV asserted their right to healthy, satisfying sex lives and that needed to be protected.

More information on sero discordant couples and Sexual Reproductive and Health Rights can also be found at, amongst other places:

http://www.unaids.org/en/KnowledgeCentre/Resources/FeatureStories/archive/

http://www.gnpplus.net/resources/sexual-and-reproductive-health-and-rights/item/33-hiv-discordant-couples-an-exploratory-study

Impact of HIV on mental/emotional wellbeing

The impact of HIV infection is quite pronounced at the individual level, where an HIV positive diagnosis can be a source of considerable psychological distress. The impact on mental wellbeing will of course be varied from one individual to the next. One of the most common causes for psychological trauma related to HIV/AIDS is the impact of social stigma on the infected individual. HIV-related stigma refers to the negative beliefs, feelings and attitudes towards people living with HIV and/or associated with HIV. This stigma can lead to feelings of depression, guilt and shame, limited participation within communities, and an increase in behaviour that may heighten the risk of further transmission. As highlighted by UNAIDS; stigma

> c*an be as devastating as the illness itself: abandonment by spouse and/or family, social ostracism, job and property loss, school expulsion, denial of medical services, lack of care and support, and violence. These consequences, or fear of them, mean that people*

[7] Rispel L.et al. (2009) Exploring Coping Strategies and Life Choices made by HIV Discordant Couples in Long-Term Relationships: Insights from South Africa, Tanzania and Ukraine, Amsterdam, GNP+. At page 9.
[8] IBID at page 37.
[9] LIVING 2008. Sexual & Reproductive Health and Rights Working Group Statement

> *are less likely to come in for HIV testing, disclose their HIV status to others, adopt HIV preventive behaviour, or access treatment, care and support.*[10]

As well the stigma projected at the individual from external sources, there is an internal part to stigma. Fears, self disablement, feelings of contamination, self rejection are some of the ways in which internal stigma manifests itself. According to a prominent HIV activist, it can be 'more insidious, and more destructive than external stigma.'[11]

Impact of stigma on disclosure of HIV status

> In the context of criminalising HIV exposure or transmission, it is important to note that stigma can reduce people's likelihood to disclose their HIV status to others.[12]

A study among Tanzanian people living with HIV found that only half of respondents had disclosed their status to intimate partners. Among those who disclosed, the average time from knowing their status to disclosure was 2.5 years for men and 4 years for women.[13] Stigma contributed to delayed disclosure.

Poor physical health, financial insecurity and other uncertainties can also have a negative impact on the emotional wellbeing of people living with HIV.

More information on stigma and the impact of HIV on emotional wellbeing can also be found at, amongst other places:

http://www.unaids.org/en/PolicyAndPractice/StigmaDiscrim/default.asp

http://data.unaids.org/pub/BaseDocument/2010/20100526_non_discrimination_in_hiv_en.pdf

Impact of Criminalisation of HIV transmission on people living with HIV

> In the 2010 report, the UN Rapporteur on the Right to Health reviewed the global context of the HIV epidemic and the application of the criminal law. With little benefit demonstrated in terms of achieving the aims of either criminal law or public health, and a corresponding risk of alienation, stigmatization and fear, the Rapporteur concluded that HIV-specific criminal offences for non-malicious HIV transmission are inconsistent with state obligations to respect, protect and fulfil the human right to the highest attainable

[10] UNAIDS (2007), Reducing HIV Stigma and Discrimination: a critical part of national AIDS programmes. Geneva: Joint United Nations Programme on HIV/AIDS

[11] Justice Edwin Cameron. Forum Lecture: "Normalising Testing – Normalising AIDS'University of KwaZulu-Natal

[12] UNAIDS (2007), Reducing HIV Stigma and Discrimination: a critical part of national AIDS programmes. Geneva: Joint United Nations Programme on HIV/AIDS.

[13] Tanzania stigma-indicators field testing group, Measuring HIV Stigma: Results of a Field Test in Tanzania. 2005, Synergy: Washington, DC.

standard of health. [14] The Special Rapporteur's report also shows that when the criminal law is misused, the outcome is a negative impact on the right to health.

The Special Rapporteur's conclusions echo the concerns expressed by PLHIV. For example, participants at a technical consultation co-organised by GNP+ and UNAIDS on "positive prevention" expressed concern that criminal laws around HIV nondisclosure, exposure and transmission may risk undermining public health by having a negative impact on the uptake of HIV testing, raising unrealistic expectations of disclosure, and hindering access to HIV prevention, treatment and care services.[15] By placing the burden of responsibility on people living with HIV, participants were concerned that these laws would undermine one of the key principles of Positive Health, Dignity and Prevention: namely, that preventing HIV transmission is a shared responsibility of all individuals regardless of HIV status[16].

Prosecuting unintentional HIV transmission or exposure to transmission has the potential to increase stigma and discrimination against people living with HIV. Research shows that most HIV is transmitted by people who are not aware of their positive HIV status. In fact the highest chance of transmission is during the early stages of HIV infection, when the viral load peaks[17]. Evidence also shows that people, who are aware of their HIV status, engage far less in high risk – unprotected – sexual contacts[18].

Impact of criminalisation on most at risk populations

Prosecuting unintentional HIV transmission or exposure to transmission has the potential to increase stigma and discrimination against people most at risk of infection with HIV, for example, men who have sex with men, injecting drug users and sex workers because are already subject to criminalisation and stigma in most countries. Criminalisation and intimidating police behaviour can make HIV prevention efforts more difficult by driving key populations away from support services. Criminalisation also has the impact of blocking the empowerment of these groups by denying or obstructing the rights to live healthy and safe lives[19].

Socio-economic impact of HIV

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14 /HRC/14/20 Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, Anand Grover (April 2010)
http://www2.ohchr.org/english/bodies/hrcouncil/docs/14session/A.HRC.14.20.pdf

15 GNP+, UNAIDS. 2009. Positive Health, Dignity and Prevention. Technical Consultation Report. Amsterdam, GNP+.

16 Ibid. At page 15.

17 Wamer, Mj, et al, Rates of HIV-1 transmission per coital act, by stage of HIV-1 infection, in Rakai, Uganda, (Journal of Infectious Diseases, 2005 May 1; 191(9):1403-9).

18 Marks G et al. Estimating sexual transmission of HIV from persons aware and unaware that they are infected with the virus in the USA. (AIDS 20(10); 1447-1450, 2006.) Summary: http://www.aidsmap.com/en/news/50971C85-3F46-4C5D-9941-035ECED21686.asp?type=preview

19 UNAIDS. http://www.unaids.org/en/KnowledgeCentre/HIVData/Epidemiology/Estimating+the+size+of+populations+most+at+risk+for+HIV.asp. Accessed on 22/06/2010.

Country level: One of the adverse impacts of the HIV epidemic on the worst hit countries is through the loss of skilled labour required for economic growth, although the extent to which this happens is debatable. Research showed that Uganda and Botswana experienced consistent economic growth between 1991 and 2002 despite having relatively HIV high prevalence in the same period[20]. On the other hand, a model analyzing the potential impact of HIV/AIDS on Ukraine, the country with the fastest growing epidemic, shows that it could experience a 1.6 percent reduction in GDP and that AIDS is likely to affect the size of the labour force significantly, with total employment declining by 10.4 percent by 2014[21]

The economic consequences of HIV in a country will depend on the ability of countries to adopt and implement policies that address HIV prevention, treatment, and care and support.

Household level: The effect of the HIV epidemic on households is varied but can be very severe in developing countries. This is especially so in settings with limited availability to treatment where high death from HIV related causes are seeing families losing their income earners. In some cases, people have to provide home based care for sick relatives, reducing their capacity to earn money for their family. Many of those dying from HIV related deaths have surviving partners who are themselves infected and in need of care. They leave behind orphans, grieving and struggling to survive without a parent's care.

In countries without social health insurance or income support, the burden care can lead to impoverishment as the long illness of a key family member leads to the diversion of labour and in the extreme cases, the selling of the household's productive assets such as farmland to raise money for medical bills.

More information on the social and economic impact of HIV can also be found at, amongst other places:
http://www.who.int/hrh/documents/Impact_of_HIV.pdf
(The impact of HIV/AIDS on the health workforce in developing countries)

Positive Health, Dignity and Prevention: an alternative to criminalisation

HIV programming is increasingly moving towards developing a more holistic focus on living positively with HIV. Positive Health Dignity and Prevention describes this new paradigm. It includes actions that assist people living with HIV to protect their general health; enjoy human rights, have fulfilling sexual relationships and community life. The term recognises the leadership role of people living with HIV in advocacy and policy change.

Rather than broad criminalisation laws, effective HIV prevention measures rely on strategies that involve people living with HIV. An international technical consultation co-organized by UNAIDS and GNP+ supported the conclusion that prevention of transmission of HIV is a shared

[20] A. Whiteside. 2008
21 USAID: Health Profile for Over all HIV Trends in Europe and Eurasia (2008).
http://www.usaid.gov/our_work/global_health/aids/Countries/eande/hiv_summary_ee.pdf

responsibility of all individuals irrespective of HIV status. Prevention is effective when PLHIV are not treated as agents for transmitting the virus, but rather supported to make choices that prevent transmission. This requires a supportive and protective legal and policy environment[22].

Protective laws and policies for people living with HIV and people most at risk of infection are essential in promoting effective HIV prevention, treatment, care and support for people.

[22]http://www.gnpplus.net/images/stories/200905_information_note_on_positive_health_dignity_and_prevention.pdf