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HIV and Legal Empowerment

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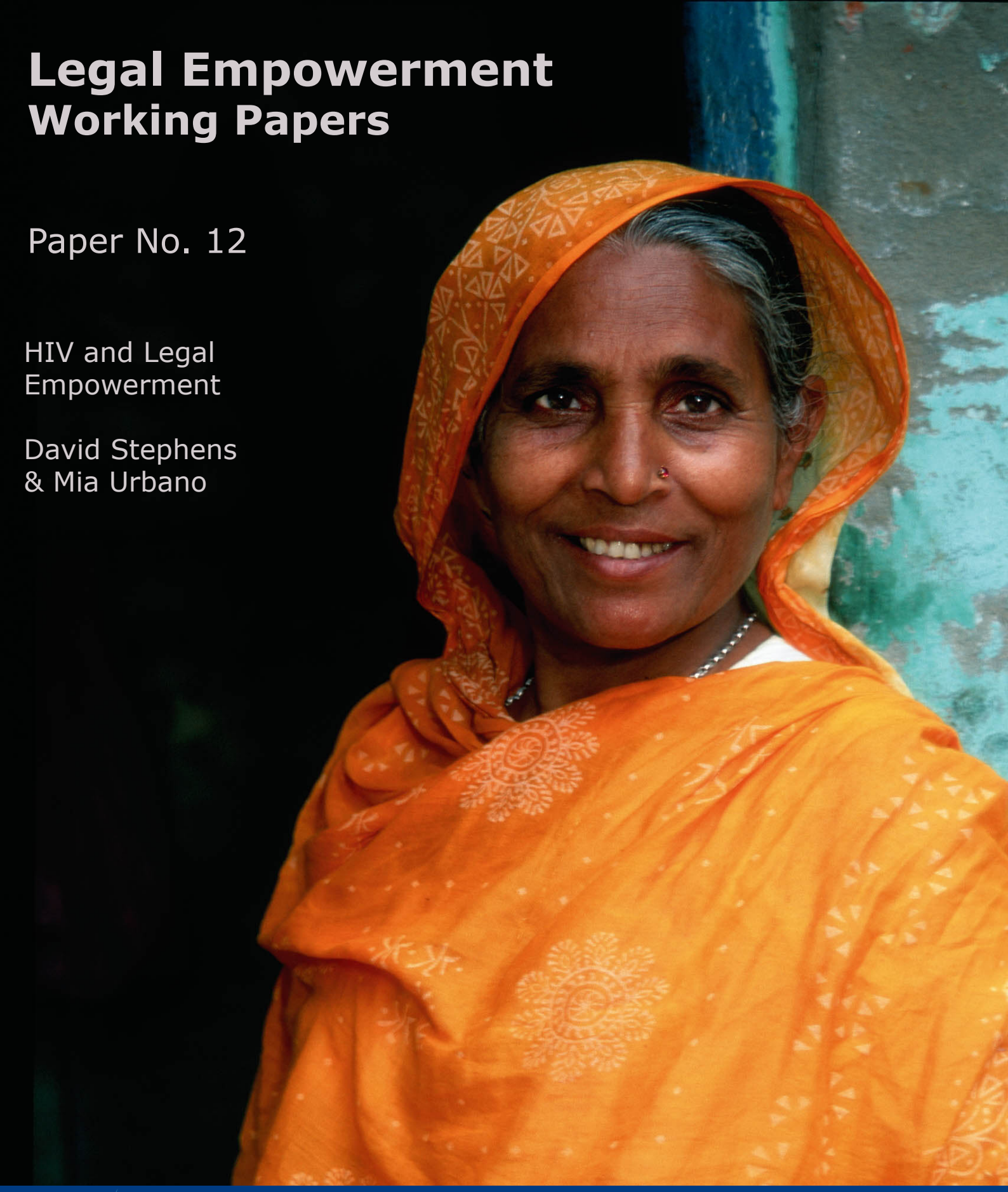

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HIV AND LEGAL EMPOWERMENT

David Stephens[1] and Mia Urbano[2]

Executive Summary

From the beginning of the HIV epidemic, the law has been the axis around which debates have revolved on the restriction or promotion of rights. Today, there is growing recognition of the role of the law in addressing discrimination against people living with HIV and empowering vulnerable people and communities. This chapter examines the central role of legal empowerment to advancing the human rights of people living with and vulnerable to HIV, and how this leads to more effective outcomes in HIV prevention, treatment and care. It explores how HIV legal empowerment strategies are evolving and the challenges they still face.

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1. Legal empowerment and responses to HIV

From the beginning of the HIV epidemic, the law has been the axis around which debates have revolved on the restriction or promotion of rights. In western industrialized countries, those most affected during the early period were gay men, injecting drug users and sex workers. These people and communities had already been marginalized by stigma and prejudice and, in many cases, involved in illegal practices. At the same time, a significant heterosexual epidemic was developing in the countries of sub-Saharan Africa. As understanding grew of the limited modes of HIV infection and of effective prevention methods, insights were gained into the importance of the structural conditions that shape HIV risk and of involving communities in HIV responses. These insights stimulated a human rights-based approach to HIV prevention and treatment. The development of effective treatments in 1996, available initially only to people in the high income countries of the global north, further highlighted the global fault lines of inequality and inequity. Today, there is growing recognition of the role of the law in addressing discrimination against people living with HIV and empowering vulnerable people and communities.

HIV transmission almost always occurs through intimate and highly personal behavior, and it takes place in environments where the capacity to exercise rational choices about safe behavior can be severely constrained by social, economic and cultural forces. Information about the effectiveness of condoms for HIV prevention, or even their possession, is of little value if the women who carry them are targeted by police, harassed and arrested because they are believed to be sex workers. This is also the case if their condom use depends on men who have little concern for the health of their sexual partners. Similarly, scientific evidence is clear on the efficacy of needle and syringe programs, opioid substitution therapy (OST) and other harm reduction approaches for reducing HIV-related harm among injecting drug users and their sexual partners.[3] Nevertheless in many countries, drug control and law enforcement approaches to illicit drug use are still largely dominated by policies and practices that show little evidence of achieving their stated aims of reducing drug use. Further, they have highly detrimental effects on HIV prevention and the health and human rights of drug users.

2. HIV, human rights and legal frameworks: a background

The law as it is applied to HIV can be classified as either proscriptive, protective or instrumental.[4] Proscriptive laws forbid specific acts, such as sexual acts between men, sex work and illicit drug use. These laws interfere with harm reduction measures and may conflict with the obligations of states to respect human rights. This category includes laws that authorize coercive practices against marginalized groups. One example is the use of extra judicial processes

[3] For an authoritative definition of harm reduction, see International Harm Reduction Association, *What is Harm Reduction?*, available at <http://www.ihra.net/Assets/2316/1/IHRA_HRStatement.pdf> at 25 September 2009.
[4] J Hamblin, 'The Role of the Law in HIV/AIDS Policy' (1991) 5(2) *AIDS* (special edition of *Current Science*) 239–243.

to detain and "treat" drug users in mandatory detention centers. There is a growing body of international evidence implicating mandatory detention in increasing HIV transmission and human rights violations.[5]

Protective laws prohibit discrimination against people living with HIV and vulnerable groups. Instrumental laws reach beyond a focus on individuals and groups to address underlying structural conditions that shape risk and vulnerability. The instrumental approach encompasses social, economic and cultural conditions that contribute to structural vulnerability to HIV. This includes laws that promote the rights of women or create the conditions in which affordable treatments can be manufactured or distributed.

Legal responses to HIV have developed in a complex and highly contested environment. The authority of medicine as the dominant discipline in determining the HIV response has been challenged by the communities most affected. Consequently, social and structural accounts of living with HIV have assumed a place alongside the bio-medical model. These structural accounts are also the principal themes of the "new public health" as it relates to HIV.

The antecedents of the new public health can be found in the improvement of health by improving living conditions. This idea is incorporated into the World Health Organization's (WHO) definition of health as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity".[6]

In the area of HIV, the new public health found its champion in Dr Jonathan Mann, the first head of WHO's Control Programme on AIDS (renamed the Special Programme on AIDS in February 1987). In 1989, WHO and the United Nations Centre for Human Rights organized an international consultation, which brought together experts from the fields of law, religion, ethics, human rights, public policy and public health to discuss HIV and human rights, including various forms of discrimination. This was the first international meeting convened to consider how international human rights instruments could be deployed to provide a template for HIV law and policy. Since then, the United Nations has been the central stage for discussions and consultations that have built on the link between HIV/AIDS and human rights.[7]

3. Legal empowerment and HIV

The concept of legal empowerment emphasizes strategies that use "legal services and related development activities to increase disadvantaged populations' control

[5] World Health Organization (WHO) Regional Office for the Western Pacific, *Assessment of compulsory treatment of people who use drugs in Cambodia, China, Malaysia and Viet Nam: an application of selected human rights principles* (2009) available at, <http://www.wpro.who.int/publications/PUB_9789290614173.htm> at 25 September 2009.

[6] Preamble to the Constitution of the WHO 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) 100) and entered into force on 7 April 1948.

[7] Office of the United Nations High Commissioner for Human Rights (UNHCHR) and the Joint United Nations Programme on HIV/AIDS (UNAIDS). 2006. *International Guidelines on HIV/AIDS and Human Rights*, Consolidated Version < http://data.unaids.org/Publications/IRC-pub07/jc1252-internguidelines_en.pdf> at 20 October 2009.

over their lives".[8] Legal empowerment is fundamentally concerned with realizing the human rights of the poor, disenfranchised and marginalized, and is community-driven. In the context of HIV, the process is driven by people living with HIV and others who may be vulnerable to, or affected by, the disease. Legal empowerment does not preclude engagement with government or legislative change. However, it is fundamentally concerned with strategies that may be more nuanced and broader than orthodox rule of law approaches, and that emerge and are driven by the needs of those at the centre of the HIV epidemic.

For a person experiencing HIV-related stigma and discrimination, a legal empowerment approach affirms and restores his or her humanity and citizenship, and supports psychological wellbeing, essential dimensions to overall welfare and health. It describes a truly holistic approach to HIV.

The view that HIV transmission is largely a result of an individual's choices or agency underlies many HIV behavioral intervention models. In this view, risks can be reduced if an individual acquires a level of knowledge and motivation sufficient to exercise personal agency to make the necessary changes.[9] For many poor and disadvantaged people around the world, vulnerability to is more associated with structural and social impediments, and infringement of their legal and human rights than access to information on behavior change and risk. In this context, the enjoyment of human and legal rights has a direct impact on a person's ability to exercise choice. Without recognition of these structural constraints, responses to HIV are partial at best. Chief among these systemic barriers for people living with HIV is stigma and discrimination.

4. HIV-related stigma

Stigma and discrimination are fundamental to understanding the HIV epidemic, both in fuelling the spread of HIV and as formidable barriers to care, support and treatment.

HIV-related stigma is a complex social phenomenon, a product of misinformation about HIV and deep-seated beliefs about disease, proscribed behaviors, sex and death. The impact of stigma is profound at the individual, community and institutional levels. Individual feelings and perceptions of stigma can become internalized causing social isolation, and depression and other mental illnesses. Stigma – actual or perceived – creates a reluctance to seek health services and reinforces the desire to remain silent about one's own HIV status. It is profoundly disempowering.

In 1963, Irving Goffman defined stigma as "an attribute that is deeply discrediting" and identified three levels, which affect, respectively, personal identity, social relations, and physical differences or defects. Goffam's model has

[8] S Golub, *Beyond Rule of Law Orthodoxy*: *the Legal Empowerment Alternative*, Carnegie Endowment for International Peace Rule of Law Series Working Paper No. 41 (2003) 3, available at <http://www.carnegieendowment.org/files/wp41.pdf> at 20 October 2009.
[9] Global HIV Prevention Working Group, *Behavior Change and HIV Prevention: (Re)Considerations for the 21st Century* (2008) available at <http://www.globalhivprevention.org/pdfs/PWG_Executive Summary_FINAL.pdf> at 12 October 2009.

provided the template for understanding HIV-related stigma, later defined by the Joint United Nations Programme on HIV/AIDS (UNAIDS) as "any measure entailing an arbitrary distinction among persons depending on their confirmed or suspected HIV serostatus or state of health".[10] Stigma exists along a spectrum that spans "self-stigma" to "enacted stigma" (i.e. discrimination). Self-stigma (sometimes referred to as "internalized" or "felt" stigma) refers to the experience in which people living with HIV accept and internalize stigmatizing views and beliefs associated with their HIV status.[11] Internalization of these negative feelings results in feelings of shame, worthlessness, self-blame and loss of self-esteem, leading to depression, withdrawal and even suicide.[12]

At the other end of the spectrum is "enacted stigma" (discrimination), which is the practical expression of stigmatizing beliefs and attitudes against people living with HIV. HIV-related discrimination can be found in the community and family as well as in institutional settings. Such discrimination takes many forms, including the exclusion of people living with HIV from family and community life and activities. Institutional discrimination includes denial of access – or reduced quality of – services, for example, in the educational or healthcare sectors.[13]

While stigma may be recognizable in different settings, its underlying drivers may be specific to a particular place and time. Because HIV-related stigma is fuelled by cultural and social constructs, beliefs and ideas, its meaning and impact will vary across and between cultural settings.[14] Stigma is also important in ways that move beyond its impact on individuals or associated practices of discrimination.[15] It must be understood and addressed as a structural and cultural force through which power operates to produce and reproduce inequalities in social relations. In this way, some groups become valued and made to feel superior, and others are devalued as stigma becomes embedded in institutions and culture.[16]

5. Discrimination

Discrimination, as defined by UNAIDS in the Protocol for the Identification of Discrimination Against People Living with HIV, is "any form of distinction,

[10] UNAIDS, *Protocol for the Identification of Discrimination Against People Living with HIV* (2000) 7.

[11] UNAIDS, *HIV-related Stigma, Discrimination and Human Rights Violations: Case Studies of Successful Programmes* (2005).

[12] P Brouard and C Wills, *A Closer Look: The Internalization of Stigma Related to HIV* (2006).

[13] S Paxton et al, 'AIDS-related Discrimination in Asia' (2005) 17(4) *AIDS Care* 413-424; C Hermann and T Leach, *Baseline Survey of GIPA and Stigma and Discrimination in the Greater Mekong Region*, an APN+ and POLICY Project report for USAID (2005), available at <http://www.apnplus.org/document/Baseline%20Survey%20of%20GIPA%20and%20stigma%20and%20discrimination%20in%20Greater%20Mekong%20Region.pdf> at 17 September 2009; O Morolake, D Stephens and A Welbourn, 'Greater involvement of people living with HIV in health care' (2009) 12(4) *Journal of the International AIDS Society*.

[14] W T Steward et al, 'HIV-related Stigma: Adapting a Theoretical Framework for Use in India' (2008) 67(8) *Social Science and Medicine* 1225-1235; M J Visser et al, 'HIV/AIDS stigma in a South African community' (2009) 21(2) *AIDS Care* 197-206; D Rao et al, 'Stigma, secrecy, and discrimination: ethnic/racial differences in the concerns of people living with HIV/AIDS' (2008) 12(2) *AIDS and Behavior* 265-71.

[15] R Parker and P Aggleton, 'HIV and AIDS-related Stigma and Discrimination: A Conceptual Framework and Implications for Action' (2003) 57(1) *Social Science and Medicine* 13-24.

[16] K Nthomang et al, 'People Living With HIV and AIDS on the Brink: Stigma – A Complex Sociocultural Impediment in the Fight Against HIV and AIDS in Botswana' (2009) 30(3) *Health Care for Women International* 233-234.

exclusion or restriction affecting a person, usually, but not only, by virtue of an inherent personal characteristic, irrespective of whether or not there is any justification for these".[17] In the case of HIV and AIDS, this is a person's confirmed or suspected HIV-positive status. Discrimination occurs at the family, community, institutional and national levels.

Responding to HIV-related stigma and discrimination remains an important component of the larger health framework for HIV and AIDS programs. As Parker and Aggleton observe,

> stigma is linked to the workings of *social inequality* (emphasis in original) and to properly understand issues of stigmatization and discrimination, whether in relation to HIV and AIDS or any other issue, requires us to think more broadly about how some individuals and groups come to be socially excluded, and about the forces that create and reinforce exclusion in different settings.18

A 2009 report by Weatherburn et al. reveals that stigma and discrimination in the United Kingdom still play a significant role in the lives of many HIV-positive people, affecting confidence, self-esteem and quality of life. Thirty-six percent of HIV-positive people (in a sample of 1,777) had experienced discrimination in the previous year, with 22 percent experiencing it from their own community and 11 percent from their own family. The authors of the report note that "the widespread experience of discrimination and social isolation point to the particular harshness of living with diagnosed HIV, compared to most other chronic conditions."[19]

A global example is the international travel restrictions imposed on people living with HIV. Travel restrictions promote the fiction that HIV can be avoided by restricting the entry of people living with HIV and legitimate public stigma. In a survey covering the 2008–09 period, 66 of the 186 countries surveyed had special entry regulations for people with HIV. Regulations in a further 22 countries are contradictory or imprecise.[20]

There have been many instances of people losing their homes and being forced out of their communities and neighborhoods due to HIV. In June 2009, the Cambodian Government began forcibly relocating families affected by HIV. The relocations were to substandard housing at Tuol Sambo, a remote site 25 km from the nearest city. The families were resettled into green metal sheds described as "baking hot in the daytime and lack[ing] in running water and

[17] UNAIDS, above n 10, 7.
[18] R Parker and P Aggleton, 'HIV and AIDS-related Stigma and Discrimination: A Conceptual Framework and Implications for Action' (2003) 57(1) *Social Science and Medicine* 13, 16.
[19] P Weatherburn et al, *What Do You Need? 2007–2008: Findings of a national survey of people with diagnosed HIV*, a Sigma Research report (2009) 2, available at <www.sigmaresearch.org.uk/go.php/reports/report2009b> at 24 September 2009.
[20] Deutsche AIDS-Hilfe e.V., *Quick Reference: Travel and Residence Regulations for People with HIV and AIDS – 2008/09* (2008) available at <http://www.hivtravel.org/Web/WebContentEATG/File/2008-2009%20Quick%20Reference%20Englisch.pdf> at September 23 2009.

adequate sanitation". The site quickly became known as the "AIDS Colony" by local people.[21]

6. The role of people living with HIV

Some of the most successful and enduring responses to HIV could not have been achieved without the creativity, activism and involvement of people living with HIV and members of communities affected by HIV. For example, the concept of "safe sex" was pioneered by activists in the gay communities of the United States. Treatment activism changed the way in which drug trials are conducted, and the approval process for the release and access to new drugs.[22] This role is encapsulated in the term "Greater Involvement of People Living with HIV/AIDS", and is often referred to as the "GIPA principle". In December 1994, at the Paris Summit on AIDS, 42 nations declared their support for the greater involvement of people living with HIV in prevention and care, policy formulation, and service delivery.

The GIPA principle has been incorporated into national and international program and policy responses, and taken up as a model of best practice in the response to HIV and AIDS. Since the Paris Summit, GIPA has been referenced in numerous international statements, including the Declaration of Commitment on HIV/AIDS endorsed by the United Nations General Assembly Special Session on HIV/AIDS (UN-GASS) in 2001.

National networks of people living with HIV provide vital community support systems and hence are well-placed to understand the legal and other challenges faced by communities, including in accessing HIV-related information and services. To ensure policies are most effective, there must be HIV community representation in policy development and implementation. Such involvement must not be tokenistic; it must value and support the expertise and insights offered by people living with HIV. Many national HIV programs now include a position for a person living with HIV. Increasing the political influence of civil society groups, especially those who represent the poor or stigmatized, is not always a comfortable choice for governments. Legal empowerment has an important role to play in supporting this process.

7. The law and national HIV responses

With few exceptions, HIV legal services remain small-scale, fragmented, and difficult to access. Even Uganda, while stabilizing HIV transmission in recent years, has "paid comparatively limited attention to the epidemic's legal and

21 CNN, HIV Families relocated to Cambodia's 'AIDS colony' (2009) <http://edition.cnn.com/2009/WORLD/asiapcf/07/28/cambodia.hiv/> at 2 December 2009.

22 See: G Gonsalves, 'ART Scale Up' (presentation given at the XVII International AIDS Conference, August 6 2008) available at <http://www.aids2008.org/Pag/PSession.aspx?s=37> 2 December 2009; P Farmer, 'Challenging Orthodoxies: the Road Ahead for Health and Human Rights' (2008) 10(1) *Health and Human Rights* 5-19, available at <http://www.hhrjournal.org/index.php/hhr/article/view/33/102> at 2 December 2009.

human rights implications. This is especially true for marginalized populations who are most vulnerable to HIV-related human rights abuses".[23]

In Thailand, the law and law enforcement agencies have played a key role in the successful reduction of HIV prevalence in the sex industry. In the early 1990s, the existence of a widespread sex industry was tacitly acknowledged, and civil society organizations and groups of people living with HIV were engaged to design, implement and enforce the first 100 percent condom use campaign. This campaign has been credited with the reduction of HIV transmission in the country's extensive sex industry. The estimated number of people living with HIV fell from 660,000 in 2001 to 610,000 in 2007. HIV prevalence amongst adults aged 15-49 years fell from 1.7 to 1.4 percent.[24]

However, this success was followed by the widely discredited Thai "War on Drugs", initiated in 2003 by the then Prime Minister Thaksin Shinawatra. Over 2,800 people were killed in the first three months of the campaign. An official investigation in 2007 found that over half of those killed had no connection with drugs at all.[25] The ferocity of this approach drove many drug users into hiding. These were people who might otherwise have sought support, information and treatment. The campaign also interrupted other public health approaches to drug use and HIV.[26]

8. Access to treatment

The development of triple combination antiretroviral therapy in the mid-1990s mobilized a global movement of researchers, advocates, community activists, people living with HIV and national governments to reduce HIV treatment costs and increase access for people in low- and middle-income countries. Access increased from approximately 300,000 people in 2002 to 3 million by the end of 2007.[27] This represented 31 percent of the estimated 9 million people in need of HIV treatment at that time.[28]

Ford et al note that Brazil and Thailand are among the few developing countries to achieve universal access to antiretroviral therapy. Ford and colleagues identify three factors critical to this success: legislation for free access to treatment;

[23] S Mukasa and A Gathumbi, *HIV/AIDS, Human Rights, and Legal Services in Uganda: A Country Assessment* (2008) viii.
[24] UNAIDS, *Country Profiles: Thailand HIV and AIDS Data*, Aids Data Hub <http://www.aidsdatahub.org/countries/profile/thailand/> at 28 September 2009.
[25] Human Rights Watch, *Thailand's War on Drugs*, an International Harm Reduction Association and Human Rights Watch briefing paper (2008) available at <http://www.hrw.org/en/news/2008/03/12/thailand-s-war-drugs> at 26 September 2009.
[26] S Sherman, A Aramrattana and D Celentano, 'Public Health Research in a Human Rights Crisis: The Effects of the Thai "War on Drugs"' in C Beyrer and H F Pizer (eds), *Public Health and Human Rights: Evidenced Based Approaches* (2007).
[27] UNAIDS, *A Global View of HIV Infection* (2007) available at <http://www.searo.who.int/LinkFiles/Facts_and_Figures_global_HIV_epidemiology.pdf> at 27 September 2009.
28 WHO, Towards Universal Access: Scaling Up Priority HIV/AIDS Interventions in the Health Sector 2008 Progress Report (2008) available at <http://www.who.int/hiv/pub/towards_universal_access_report_2008.pdf> at 17 September 2009.

public sector capacity to manufacture medicines; and strong civil society action to support government initiatives to improve access.[29]

In 1996, the Government of Brazil legislated to provide antiretroviral drugs through the public health system.[30] The impact of HIV in Brazil resonated with existing social justice and developmental concerns, and catalyzed affected communities to mobilize both socially and politically. Mobilization was based not only on HIV status, but also on other socially excluded identities, in particular homosexuals, sex workers, transgender people, and injecting drug users. In August 2005, proactive leadership by Brazil was an important factor in regional negotiations held between 11 Latin American governments and 26 pharmaceutical companies, which resulted in a 15 to 55 percent price reduction for the treatment regimens most commonly used in the region.[31]

In Thailand, the Thai Network for People Living with HIV/AIDS in alliance with the Law Society of Thailand, academics, consumer groups and activists launched a legal action to revoke Bristol Myers Squib's (BMS) Thai patent on didanosine (DDI), which was an important HIV drug at the time. BMS subsequently relinquished its patent on DDI in Thailand. The DDI case established the important precedent for consumers to be termed "interested parties" in Thai patent law. Prior to this case, interested parties only included rival companies, not potential consumers of the drugs.[32]

In 2006, the Health and Development Foundation of Thailand challenged GlaxoSmithKline's application for a patent on a combination of the drugs zidovudine/lamivudine in a fixed dose on the basis that the combination was "nothing new". The drug had been produced since 2003 in generic form by the Thai Government Pharmaceutical Organization (GPO) at a retail price of approximately US$276 per patient per year. If the patent had been granted, the cost would have increased to US$2,436 per patient per year. The same legal challenge was filed by civil society groups in India, and activists in both countries coordinated their campaigns.[33] GSK withdrew the patent application in both countries, asserting that it did so prior to demonstrations in India and Thailand. GSK nonetheless stated that the "focus on patents in addressing the challenges of HIV/AIDS is misguided and counterproductive".[34]

In South Africa, the Treatment Access Campaign (TAC) embodies an approach where legal action, advocacy and social mobilization are brought together in the pursuit of human rights objectives. TAC was founded in 1998 to support access to HIV treatment, care and support, and to provide resources for people living with HIV in South Africa. The TAC objectives are to:

[29] N Ford et al ,'Sustaining Access to Antiretroviral Therapy in the Less-Developed World: Lessons from Brazil and Thailand' (2008) 21(4) *AIDS* s21-29.
[30] K Safreed-Harmon, *Human Rights and HIV/AIDs in Brazil* (2007) The Body <http://www.thebody.com/content/art45452.html> at 28 September 2009.
[31] Pan American Health Organization, *Towards Universal Access to HIV Prevention, Care and Treatment*, a 3 by 5 report for the Americas (2006) 30.
[32] B Tenni, S R Smith and K Bhardwaj, *Our Health Our Right: the roles and experiences of PLHIV networks in securing access to generic ARV medicines in Asia* (2008) .
[33] Ibid 32.
[34] Open letter from GlaxoSmithKline (GSK) regarding GSK patents and patent applications directed to a specific application of Combid/Combivir, 9 August 2006, Bangkok, Thailand.

> challenge by means of litigation, lobbying, advocacy and all forms of legitimate social mobilization, any barrier or obstacle, including unfair discrimination, that limits access to treatment for HIV/AIDS in the private and public sector.[35]

TAC first took the South African Government to court for its failure to assure antiretroviral therapy to prevent mother-to-child transmission (MTCT). TAC won the case on the basis of the South African constitutional guarantee of the right to health care, and the government was ordered to provide MTCT programs in public clinics.36 In 2000, TAC joined the South African Government in the litigation concerning the challenge to South Africa's Medicines Act by international pharmaceutical companies. In 2001, the pharmaceutical companies unconditionally withdrew their lawsuit as a result of a combination of stringent public criticism and the legal arguments prepared by TAC and the South African Government. This was prompted by very negative publicity generated by demonstrations outside the court house where the case was being heard and televised around the world.

High profile and highly publicized court cases are but one aspect of the movement for treatment access around the world. Social mobilization and community activism are central to ensuring a deeper and broader sense of empowerment and understanding of what human rights can achieve for movements such as TAC. The core of TAC's work in community empowerment is located within its treatment literacy programs with poor people. These programs provide the foundation for community based human rights advocacy, which demands "the delivery of health care services within poor communities as a matter of right and law".[37]

9. Vulnerable communities

Law reform to create a framework to address HIV-related stigma and discrimination must take into account the vulnerability and associated stigmas attached to specific communities, lifestyles and behavior. In a review of legal frameworks and human rights as they relate to sexual minorities in low- and middle-income countries, Cáceres et al. found that social exclusion remained the overwhelming reality for the majority of gay, bisexual transgender and other men who have sex with men (MSM).[38] This situation is sustained by: unjust laws that criminalize same sex relations and sexual diversity; cultural norms or barriers that inhibit the promotion of HIV prevention care and treatment among sexual minorities; and deficiencies in health planning that do not account for the relative invisibility of sexual minorities or conversely, that over-identify them with HIV, which leads to further stigmatization. Repressive legal frameworks still exist in

35 Cited in M Heywood, 'South Africa's Treatment Action Campaign: Combining Law and Social Mobilization to Realize the Right to Health' (2009) 1(1) Journal of Human Rights Practice 14, 15, available at <http://jhrp.oxfordjournals.org/cgi/reprint/1/1/14> at 2 December 2009.
[36] Treatment Action Campaign v. Minister of Health : Case in Brief, available at <http://www.law-lib.utoronto.ca/diana/TAC_case_study/CASEINBRIEF.pdf> at December 3 .
37 M Heywood, 'South Africa's Treatment Action Campaign: Combining Law and Social Mobilization to Realize the Right to Health' (2009) 1 (1) Journal of Human Rights Practice 19.
[38] C F Cáceres et al, *Review of Legal Frameworks and the Situation of Human Rights related to Sexual Diversity in Low and Middle Income Countries*, study commissioned by UNAIDS (2008).

countries in sub-Saharan Africa, the Caribbean, the Middle East and North Africa, South Asia, East Asia, and the Pacific.[39]

A 2008 report by the International Lesbian and Gay Association, which undertook a similar survey, notes that even if these countries do not enforce repressive laws, their very existence reinforces and gives legitimacy to cultures of homophobia and discrimination.[40] In 2009, nine men in Senegal were sentenced to eight years in prison for "committing acts against nature" and "establishing an illegal organization". All were members of an AIDS service organization (AIDE) that provided HIV prevention services to marginalized groups, including MSM.[41]

Activists are challenging repressive legal frameworks in the courts. As a result, in 2009, the Delhi High Court, New Delhi, India, overturned a 148-year old colonial law criminalizing consensual homosexual acts as a violation of fundamental human rights protected under India's Constitution.[42]

10. Drug users

Outside sub-Saharan Africa, injecting drug use accounts for one in three HIV infections.[43] It is estimated that there are about 16 million people who inject drugs globally[44] and that 78 percent of injecting drug users live in developing and transitional countries. The largest numbers of injectors are found in China, the United States of America and the Russian Federation.[45]

The criminalization of drug use impacts directly on HIV prevention activities. Laws that criminalize the possession of needles and syringes enable police harassment and arrest of drug users. These laws also allow the compulsory and extrajudicial detention of drug users in centers where they are forced to undergo detoxification with little or no medical support. In many countries, there have been moves towards the resolution of legal and policy conflict between drug control and harm reduction frameworks. However, there remains a continuing reliance among drug control and law enforcement actors on punitive approaches.

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[39] Cáceres et al classify "highly repressive" frameworks as the legal frameworks that criminalize sodomy and impose severe penalties such as death, heavy labor, imprisonment for at least five years while "moderately repressive" frameworks are legal frameworks that criminalize sodomy and impose penalties of less than five years, ibid 8.

[40] D Ottosson, *State-Sponsored Homophobia: a world survey of laws prohibiting same sex activity between consenting adults* (2007) 4, available at <www.ilga.org/statehomophobia/State_sponsored_homophobia_ILGA_07.pdf> at 2 December 2009.

[41] Global Forum on MSM & HIV, 'Jail sentences for gay men in Senegal undermine human rights and the fight against AIDS' (press release January 15 2009) <http://www.msmandhiv.org/documents/JailsentencesforgaymeninSenegalunderminehumanrightsandthefightagainstAIDS.pdf> at 23 September 2009.

[42] ILGA, *Indian High Court: Gay Sex is Legal* <http://www.ilga.org/news_results.asp?languageid=1&fileid=1267&zoneid=3&filecategory=1> at 23 September 2009.

[43] Open Society Institute, *Breaking Down Barriers: Lessons on Providing HIV Treatment to Injection Drug Users* (2004).

[44] B M Mathers et al, 'Global Epidemiology of injecting drug use and HIV among people who inject drugs: a systematic review' (2008) 372(9651) *The Lancet* 1733 – 1745, available at <http://www.thelancet.com/journals/lancet/article/PIIS0140673608613112/abstract > at 24 September 2009.

[45] C Aceijas et al 'Global overview of injecting drug use and HIV infection among injecting drug users' (2004) 18(17) *AIDS* 2295-2303.

Harm reduction policy is heavily influenced by the "war on drugs". In the 1970s, the Nixon Administration in the United States aimed to reduce drug demand by reducing drug supply. This has resulted in a global, regional and national architecture of narcotic agreements, and law and financing arrangements. In 2004 alone, the US Government spent almost US$12.1 billion on the War on Drugs Campaign.[46] In 2008, Paul Hunt, the then United Nations Special Rapporteur on the Right to the Highest Attainable Standard of Health, noted that the United Nations Commission on Narcotic Drugs is almost exclusively concerned with the three conventions on drug control and pays "scant regard for the international code of human rights that emerges from one of the principal objectives of the UN Charter".[47]

11. Legal services

Legal services provide case-based support for people with HIV and vulnerable populations. In addition to client case work, legal services can play a powerful role in improving the understanding of HIV legal and policy frameworks through information and education, and through training for law enforcement actors, health workers, clients of services and the general public.[48]

In Viet Nam, the HIV legal clinic in Ho Chi Minh City provided advice to over 200 people during the first six months of operation in 2007.[49] In Ukraine, a variety of approaches has been used to strengthen legal support to drug users through health services. These include employing a lawyer on site, and contracting legal firms to provide services as needed.[50] The Street Lawyers (*Gadejuristen*) of Copenhagen provide another model of legal assistance to street-based drug users. This organization provides legal aid to the most disadvantaged drug users in the city. In addition to sterile injecting equipment, they distribute pocket-sized cards with questions and answers about drug laws and harm reduction.[51] Other services train HIV-positive people and drug users to know their rights and advocate on behalf of themselves and their friends and peers when they are arrested or harassed by the police or refused access to services,[52] and provide training for lawyers and judges through professional associations.[53]

Organizations such as the AIDS Law Project in South Africa are engaged in legal support for individuals affected by HIV, and in the broader mission of law and

[46] US Office of National Drug Control Policy, *National Drug Control Strategy: FY 2005 Budget Summary* (2004) 1.
[47] P Hunt, 'Human Rights, Health and Harm Reduction: States' Amnesia and Parallel Universes' (an address to the 19th Conference of the International Harm Reduction Association, Barcelona, May 11 2008, 9) available at <http://www.ungassondrugs.org/images/stories/hunt.pdf> at 25 September 2009.
[48] IDLO, UNAIDS and UNDP, *Toolkit: Scaling Up HIV-related Legal Services* (2009).
[49] Health Policy Initiative, *HIV/AIDS Legal Support Services in Viet Nam* (2007) unpublished briefing paper, on file with author.
[50] C Carey and A Tolopilo, *Tipping the Balance: Why Legal services are essential to health care for Drug Users in Ukraine*, an Open Society Institute report (2008).
[51] HCLU Films, *Gadejuristen – The Danish Street Lawyers* (2009) Drug Policy Website of the Hungarian Civil Liberties Union 2009 <http://drogriporter.hu/en/gadejuristen> at 25 September 2009.
[52] M Davis, *Street Lawyering in Jakarta* (2009) Asia Catalyst <http://asiacatalyst.org/blog/2009/02/street-lawyering-in-jakarta.html> at 24 September 2009.
[53] H Chung, *HIV/AIDS Human Rights Seminar* (2003) The Malaysian Bar <http://www.malaysianbar.org.my/human_rights/hiv/aids_human_rights_seminar.html> at 24 September 2009.

policy reform. In alliance with other national actors, such as the Treatment Action Coalition, they advocate for change to the underlying structural conditions that increase HIV vulnerability of the marginalized and poor in South Africa.[54] The AIDS Law Project convenes the South African Budget and Expenditure Monitoring Forum. The forum is comprised of HIV organizations and reviews provincial health budget allocations to ensure they are adequate to meet the need for HIV treatment.[55]

12. Criminalization of HIV transmission

A significant challenge to the legal empowerment model is the increasing use of the criminal law in the context of HIV transmission ("the criminalization of HIV transmission"). The debate on criminalization balances criminal law and public health, and personal versus shared responsibility for protection from HIV transmission. The public health community has generally not favored the use of criminal law as a tool to deter transmission of HIV. Typical prevention programs aim to provide people with the information and resources necessary to avoid infection. The criminal law has been used as a last resort for exceptional cases not amenable to public health approaches.

Since 2004, nine West African countries have introduced national legislation based on a "model HIV law" that criminalizes the transmission of HIV if the infected person has knowledge of his or her HIV status, regardless of any intention to do harm.[56]
The move towards criminalization of HIV transmission is partly motivated by the need to create meaningful legislative protection for women in Africa, who are often infected through sexual oppression and violence.[57] However, because women are more likely to come into contact with health services (particularly in the context of pregnancy), they are also more likely to be diagnosed with HIV before their sexual partners. They may then be accused, often inaccurately, of "bringing HIV into the home", exposing them to violence, expulsion from the family home and criminal prosecution. When viewed from a gender perspective, such well-intended laws can have unintended negative effects.

There are other compelling reasons why the criminal law may be inappropriate:

- Criminalization of HIV transmission legitimates discrimination against people living with HIV and reinforces the quarantine mentality of "us" and "them".

[54] AIDS Law Project, *About Us* <http://www.alp.org.za/?option=com_content&task=view&id=48> at 28 September 2009.
[55] AIDS Law Project, *ARV Programmes Under Threat Due to Budgeting Failures* <http://www.alp.org.za/index.php?option=com_content&task=view&id=92> at 28 September 2009.
[56] S Burris and E Cameron, 'The Case against Criminalization of HIV Transmission' (2008) 300(5) *JAMA* 578-581.
[57] R Jürgens et al, *10 Reasons to Oppose Criminalization of HIV Exposure or Transmission* (2008) 1, available at <http://www.soros.org/initiatives/health/focus/law/articles_publications/publications/10reasons_20080918/10reasons_20081201.pdf> at 26 September 2009.

- It ignores public health knowledge of measures that prevent HIV transmission, and acts as a powerful deterrent to people knowing their status *voluntarily*.
- Fear of criminal sanctions drive people vulnerable to or living with HIV away from the very services they need to support them.
- It jeopardizes the relationship with carers who hold information on a person's status that could be relevant to criminal proceedings; it violates the confidentiality of a provider-patient interaction, and a person's right to privacy.
- Criminalization also reverses the progress made on countering taboos and the silence on sexuality, sexual health and lifestyles.
- Given the resource-intensity of criminal proceedings and court caseloads, it is likely that HIV-related prosecutions will be few and sensationalized. The overwhelming impact will be to discourage voluntary testing and exacerbate stigma.[58]

Consequently, UNAIDS urges governments to limit prosecution of transmission to cases where there is a clear intention to transmit the virus.[59]

Laws that are *indirectly* intended to reduce vulnerability to HIV infection, such as those to protect vulnerable groups from sexual exploitation and trafficking, can also have unintended consequences.[60] In Cambodia, the Law on Suppression of Human Trafficking and Sexual Exploitation, introduced in 2008, has been used by police to close brothels and arrest sex workers. It has significantly reduced HIV prevention activities with sex workers and drug users. More than 500 women were arrested for soliciting sex in the first nine months of 2008, according to the anti-trafficking organization *Agir pour les femmes en situation précaire* AFESIP, with many of them forced into rehabilitation centers. One result of this law is that sexually-transmitted infections including HIV will likely increase because sex workers are reportedly not carrying condoms out of fear they will be used as evidence against them.[61]

12. HIV, legal empowerment and gender

Since the late 1990s, globally, about 50 percent of people living with HIV have been female. Women and girls represent an increasing proportion of new infections in several regions, notably sub-Saharan Africa, with rates as high as 60 percent.[62] In certain countries, there are two to five times the number of young women (aged 15–24) living with HIV than their male peers.[63]

[58] Ibid 19.
[59] UNAIDS, *UNAIDS Policy Brief: Criminalization of HIV Transmission* (2008).
[60] L Gable, L Gostin, J G Hodge Jr, 'A Global Assessment of the Role of Law in the HIV/AIDS Pandemic' (2009) 123(3) *Public Health* 260.
[61] *New Sex Law Brings Problems* (2008) The New Straits <http://www.straitstimes.com/Breaking%2BNews/SE%2BAsia/Story/STIStory_318576.html> at 25 September 2009.
[62] UNAIDS, *2008 Report on the Global AIDS Epidemic* (2008) 14.
[63] Ibid.

UNAIDS estimates that one-third of countries globally lack legislation protecting people living with HIV from discrimination. The impact of this is compounded for women living with HIV. First, women in general endure disparities in protection and recognition of their rights under law. Discrimination is embedded in the statutory and customary laws and practice of many countries. Second, owing to the pervasive economic, social and legal dependence of women on male family members, they can suffer injustices both as women living with HIV, and as women affected by HIV, for instance, through the death of an HIV-positive husband. In 2001, all United Nations Member States undertook to take measures to respond to HIV, including addressing the impact on women and girls.[64]

In 2008, an international expert group reviewed good practices in legislation on violence against women.[65] In many countries, women are deprived of equal rights relating to land tenure, inheritance, marriage, custody and divorce, and access to credit. Denial of legal protections for women generates and exacerbates poverty, homelessness, insecurity, exposure to physical and sexual violence, and health harm. A 2007 study in Botswana and Swaziland reported that:

> women who lack sufficient food are 70 percent less likely to perceive personal control in sexual relationships, 50 percent more likely to engage in intergenerational sex, 80 percent more likely to engage in survival sex, and 70 percent more likely to have unprotected sex than women receiving adequate nutrition.66

Laws that authorize the marriage of "minors" (i.e. under 18 years) also increase HIV vulnerability. UNAIDS reports that early marriage is the overwhelming risk factor for HIV transmission among young girls in low- and middle-income countries. Young married women have more frequent unprotected intercourse than their unmarried peers, and with typically older husbands, and have less ability to negotiate sexual encounters.[67]

The following two examples illustrate the importance of enhanced legal protection and empowerment of women living with or affected by HIV.

12.1 Property and inheritance rights

Women's equal right to property is clearly established under international human rights law. Article 16 of the United Nations Convention on the Elimination of All Forms of Discrimination Against Women (1979) requires States to:

> take all appropriate measures to eliminate discrimination against women in all matters relating to marriage and family relations and in particular to

[64] United Nations General Assembly, Declaration of Commitment HIV/AIDS, A/RES/S-26/2 (2001) Para. 59.
[65] Canadian HIV/AIDS Legal Network, 'Legislating for women's rights in the context of the HIV pandemic: Draft legislation project description' (supporting paper EGM/GPLVAW/2008/SP.02 prepared for the UNODC and UNDAW Expert Group Meeting on good practices on legislation on violence against women, May 2008).
[66] UNAIDS, above n 65, 73 citing S D Weiser et al, 'Food Insufficiency is Associated with High-risk Sexual Behavior among Women in Botswana and Swaziland' (2007) 4(10) *PLoS Medicine*.
[67] UNAIDS, above n 65, 107-9.

> ensure, on a basis of equality of men and women… the same rights for both spouses in respect of the ownership, acquisition, management, administration, enjoyment and disposition of property.

Land is the single most important source of wealth, and allows households to adapt to and survive financial and familial shocks and losses. Land provides food, nutrition, shelter, access to water, energy (i.e. gas and electricity) and sanitation. Productive land is paramount in agriculture-based economies where it also provides access to employment and income.

Laws and practices pertaining to the use, ownership, management and disposal of property are instrumental in the cycle of HIV risk, illness and poverty.[68] Sex-disaggregated data on the scale of women's property ownership is piecemeal, but indications are predictably low. For instance, in Nepal, rates of female land ownership reach 25 percent; in Pakistan women own less than 3 percent of the land they till; and in Cameroon, women own a mere 10 percent of the land despite doing 70 percent of the agricultural work.[69]

In many countries, national laws restrict women's ability to own and inherit property. Although customary law in several sub-Saharan African countries prescribes that women should receive maintenance from the male heir of the deceased person (e.g. the woman's husband or father), this practice has virtually disappeared. Further, women's indirect contributions to the acquisition of property go largely unrecognized. In countries where the title deeds are vested in the male head of household, women are without secure tenure upon the death of or divorce from their husband. In this environment, women have a strong structural impetus to endure abusive or violent relationships, or polygamous marriages. After the death of their male partner, women may be evicted from their homes, and face property grabbing, stealing of their children and even accusations of witchcraft.[70]

Women who lose their property or are evicted are often forced to accept undesirable living, family and working conditions. Research from South Africa has found that women will sometimes engage in transactional sex as a way of resolving basic needs, such as food security, but also as a means of temporary shelter.[71] Rural women who lose access to land may be forced to migrate to urban areas, leaving behind social support networks and often their children. Without property collateral, women live with the constant threat of destitution, which is amplified for those who head households and are primary carers.

Women whose property and inheritance rights are upheld are better equipped to cope with the unpredictable course of HIV-related illness, and intimate and

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[68] R Strickland, *To Have and To Hold: Women's Property and Inheritance Rights in the Context of HIV/AIDS in sub-Saharan Africa*, International Center for Research on Women-Information Brief (2004) 2, available at <www.icrw.org/docs/2004_info_haveandhold.pdf> at 2 December 2009.
[69] P Nanda, 'Drawing Conceptual Linkages: Property Rights and HIV' (2008) 13(2-3) *HIV/AIDS Policy and Law Review* 84.
[70] Canadian HIV/AIDS Legal Network et al, Statement E/CN.62009/NGO submitted to the Commission on the Status of Women, Fifty Third Session, 2-13 March 2009.
[71] International Center for Research on Women, *Women's Property Rights, HIV and AIDS and Domestic Violence: Research Findings from Two Districts in South Africa and Uganda* (2007) 145-6.

economic losses, including lost wages for the ill person or carer, antiretroviral therapy and health care costs, and even funeral arrangements. Property allows for land and household assets to be sold and monetized, confers guarantees for access to credit, and provides food security through access to land and liquefiable assets. Although less tangible, securing property rights for women provides physical and psychological security in circumstances of loss and precariousness, and empowers women to cope with HIV and take positive action to mitigate its impacts.

NGOs are initiating programs to address the property rights of women in the context of HIV. In the United Republic of Tanzania, the Gender and Poverty Project, implemented by the Women's Legal Aid Centre (WLAC), promotes gender equality in property rights. Equality in property matters is recognized under local legislation; however, rural women in particular find themselves subject to traditional, patrilineal norms. WLAC provides comprehensive support and redress to women facing eviction and inheritance theft. Many of its clients are women living with HIV. WLAC holds community education campaigns to promote understanding of women's rights to property ownership, title deeds and to have a mortgage among the judiciary, law enforcement personnel and community. WLAC also offers a legal service for women to pursue property claims through legal action and the court system.

Adopting a community mobilization approach, the Women's Property Ownership and Inheritance Rights Project (KWPOI) in Kenya, which partners with the Kenya National Commission on Human Rights, engages with cultural institutions that informally govern rural communities to educate them on the property rights of women living with HIV and widows, and HIV widows KWPOI works with local elders to raise their awareness of statutory laws and the hardships faced by women in their communities. It also highlights traditional social norms that can be applied for the protection of women and widows. The approach is regarded as more "socially acceptable and accessible" than recourse to formal legal processes.[72]

Using HIV clinics as a contact point, The AIDS Support Organisation (TASO), based in Uganda, provides care for people living with HIV and AIDS. When clients – 65 percent of whom are women – seek care and treatment services, TASO counselors provide information and encourage discussion of related legal matters, such as property and inheritance. TASO actively monitors policy directions and legislation regarding women's rights.[73]

Given the complexity of property regimes, diversity in the degrees and kinds of women's access to and use of property, and the overlay of customary laws, research is needed to comprehend the particular impact of these factors on women in various settings.

[72] Organisation for Economic Co-operation and Development (OECD), 'Women's Empowerment and HIV Prevention – Donor Experience' (Room Document No. 2 prepared for the Development Assistance Committee (DAC) Network on Gender Equality, 27–29 June 2007, unedited draft) 31, available at <www.oecd.org/dataoecd/51/19/38759356.pdf> at September 25 2009.
[73] Strickland, above n 70, 7.

12.2 Sexual and reproductive health rights

The right to access and exercise choice over one's sexual and reproductive health is enshrined in international human rights law. Article 12 of the Committee on the Elimination of Discrimination against Women (CEDAW) directs States to "take all appropriate measures to eliminate discrimination against women in the field of health care in order to ensure, on a basis of equality of men and women, access to health care services, including those related to family planning". However, women are subject to abuse such as violations of their sexual and reproductive rights in multiple ways, which are amplified for women living with HIV.

Among the grave violations of women's rights is mandatory HIV testing. Confidential and voluntary testing and counseling is fundamental to respect for women's reproductive autonomy and privacy. Mandatory testing may be authorized by law or may occur in the absence of legal prohibitions. It can also occur in countries where it is unlawful, but applied in practice, especially by health facility directives. For example, Kenya has regulations requiring informed consent for HIV testing, but a study by the United Nations Population Fund (UNFPA) and WHO found that only "half of its public health facilities and 15 percent of its maternity facilities follow them".[74] Compounding the violation of reproductive rights and of a woman's bodily integrity, mandatory testing is often combined with breaches of confidentiality about the test result. This places women at risk of violence, ostracism or neglect by their partners and families, and can trigger the property and economic insecurities described above. Mandatory testing for all pregnant women also acts as a powerful discouragement to seeking antenatal care, which establishes crucial contact with women for early detection or timely referral of obstetric complications.

The coerced sterilization of HIV-positive women is increasing in several regions. These measures are directed to preventing the transmission of HIV to a foetus, and are often the outcome of mandatory HIV testing relating to routine medical procedures. Coerced sterilization has been documented by *Vivo Positivo* in Chile and by the International Community of Women Living with HIV/AIDS in South Africa and Namibia. In some cases, the women are not counseled about the risk of HIV transmission to the child, and the available ways to reduce it. Cases have also been reported where a woman's sterilization is made a pre-condition for obtaining access to other health services.[75]

Several organizations in sub-Saharan Africa have integrated legal services within health care clinics. These are designed to provide holistic care and access to justice for HIV-positive women who have faced abuse and discrimination. The Christian Health Coalition in Kenya provides legal services to women in 30 of its HIV clinics. CARE has added paralegal services to a microfinance initiative to support women to improve their economic security and redress rights violations.

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[74] X A Ibanez, 'Abuses of Women's Rights in Sexual and Reproductive Health Care settings' (2008) 13(2-3) *HIV/AIDS Policy & Law Review* 82 citing UNFPA and WHO, *Sexual and Reproductive Health of Women Living with HIV: Guidelines on Care, Treatment and Support for Women Living with HIV/AIDS and their Children in Resource-Constrained Settings* (2006).
[75] Ibid 82.

Conclusion and recommendations

A central insight from this overview of legal empowerment and HIV is the importance of the inclusion of people living with HIV and affected communities in addressing social vulnerability and injustice. The authors propose a number of broad recommendations to support HIV-related legal empowerment.

(i) greater investment in HIV-related legal services and expansion of existing services to increase community reach. This should include investment in emerging service models, e.g. formal services hotlines, mediation tribunals, centers and outreach, referral pathways, law reform linkages, medico-legal partnerships;

(ii) universal access to legal services incorporated into the advocacy agenda of organizations working with vulnerable populations and people living with HI;.

(iii) development and implementation of legal services as part of a comprehensive continuum of HIV prevention, care and treatment services;

(iv) increased legal empowerment through rights education. In parallel with law reform, there is a need to raise the awareness of women and men living with HIV of their rights, especially as protection gaps under law are addressed. Education needs to include information on legal and human rights, their infringement and consequences, and options for redress;

(v) improved competence of legal services and practitioners on HIV-related matters. Raise awareness of legal providers to the evidence and myths of HIV to support non-judgmental lawyer-client interactions. This could also be expanded to include HIV-related modules within tertiary-level law curriculum and legal practice training;

(vi) support in the training and development of paralegal capacity among people living with HIV and their representative networks and organizations;

(vii) increased research in critical areas on the impact of legal frameworks on men and women living with and affected by HIV: This should include laws criminalizing HIV transmission, narcotic control legislation, extra judicial detention of drug users, as well as laws prohibiting sexual acts between men;

(viii) applied research on the impact of legal aid and support programs, for example in relation to the role of legal empowerment in increasing HIV prevention, treatment and support outcomes;

(ix) investment in developing strategic legal empowerment fora, for example, an international conference or series of regional conferences on the role of the law in HIV responses, including human rights and legal empowerment.