

Unit 5: The Legislative Role of Parliamentarians in the Fight against HIV/AIDS

Learning Objectives

How do parliamentarians legislate to improve the response to HIV/AIDS?

After studying this unit, you should be able to:

- Have improved knowledge of the rationale and requirements for HIV-specific legislation;
- Understand the *International Guidelines on HIV/AIDS and Human Rights* and the rights-based approach to HIV legislation;
- Be aware of examples of legislative implications when addressing various HIV/AIDS policies and programs;
- Identify key resources available to assist in the drafting, review and enactment of HIV legislation.

Introduction

Parliamentarian's responsibility to review and enact legislation makes them key actors in the fight against HIV/AIDS. Because of the far-reaching impacts of the pandemic, legislation is required in a number of areas to ensure adequate HIV prevention, treatment, care and support programs as well as the protection of the rights of those infected and affected by the disease.

Unit 5 explores the legislative implications of HIV/AIDS and provides some key resources that parliamentarians can refer to when making decisions on HIV-related laws and legislative reform which includes a human rights-based approach.

The Need for HIV-Related Legal Frameworks

In adopting the *UNGASS Declaration of Commitment on HIV/AIDS* and numerous other international commitments on HIV/AIDS (see Unit 3), the heads of State and representatives of Governments from the 189 member states of the UN General Assembly have endorsed the notion that the protection of human rights and gender

equality is fundamental to the fight against the pandemic. These governments have also recognized that appropriate legal frameworks are required to ensure effective national responses.

The adoption of laws that incorporate the protection of human rights and gender enables those vulnerable to HIV infection access to prevention mechanisms and allows those living with HIV to live free from stigma and abuse. Yet reform of discriminatory law in many countries is lagging, partly due to the fact that measures such as HIV education and information required to sensitize judges, police officers, policy makers and other officials on the appropriate enforcement of the law is also absent. The result is that human rights abuses and the fear of such abuse and discrimination continue to increase vulnerability to HIV infection.

Box 1

Legislation Protecting Individuals from Abuse and Discrimination still Lagging in sub-Saharan Africa

Upon review of several reports, it is clear that the issue of abuse in sub-Saharan Africa remains a "private affair", and policy, where it exists, is rarely enforced. This can be seen in cases of gender based violence, which continues to persist in the region. Non-existent legislation or ignorance about their rights leaves women vulnerable to physical, emotional, sexual, and economic abuse.

Looking first to Uganda, Human Rights Watch (HRW) denounced the Ugandan government for its failure to protect women from domestic violence and discrimination. In their report HRW confirmed the link between these abuses and the risk of HIV infection. As of 2003 Uganda had yet to specify domestic abuse law protecting women from not only violence, but also marital rape. According to the Director of the Women's Rights Division of HRW, "the Ugandan government's failure to address domestic violence is costing women their lives" and that "any success Uganda has experienced in its fight against HIV/AIDS will be short lived if the government does not address this urgent problem." Many women told Human Rights Watch that the fear of violent repercussions lessened their access to HIV/AIDS information, testing, treatment and counseling.

In 2003 Human Rights Watch urged the Ugandan government to enact domestic violence legislation, and to make women's health, physical integrity, and equal rights central to their AIDS programming. For more than a decade, women's groups in Uganda have also pressured the government to enact legislation; however the bills have languished in parliament. This remains true in 2008 as Uganda still lacks specific legislation.

Conversely, Zimbabwe has successfully implemented new domestic violence laws as recently as 2007, however implementation of laws is lagging as national policy continues to contradict customary law. The Zimbabwe Women Lawyers Association (ZWLA) remains concerned that

despite the provision of the Domestic Violence Act, a growing number of domestic violence cases remain uncharged. A ZWLA representative claimed that many victims are still unaware of the rights made available to them under the law, as not enough has been done to publicize the existence of the law, especially in rural areas.

Furthermore, the paperwork required to prosecute cases of domestic violence are not only esoteric, but lengthy. The form required is 30 pages, according to ZWLA, which is too long and complicated for someone who has been subjected to physical and emotional abuse. The ZWLA urges the government of Zimbabwe to streamline the process, and to make the forms more accessible to victims.

Another problem with prosecuting domestic violence is the issue of cultural attitudes which reinforce the belief that women are second class citizens or the physical property of their husbands. According to the Uganda Law Reform Commission, violence appears to be entrenched in cultural traditions that do not allow for the concept of sexual consent among women. Women succumb to coerced sex for fear of further sexual or physical violence. Furthermore, the custom of paying a "bride price" keeps women in abusive relationships as women may be dissuaded from leaving the abusive situation for fear of having to return the "bride price" which is often not economically feasible.

Economic vulnerability of women may leave many cases of abuse unreported, as women do not wish their husbands to be jailed or punished too severely, as it is seen to compromise their economic security.

Enforcement of such laws can also be frustrated by the attitudes of judges and judicial officers who prosecute perpetrators leniently, or simply do not wish to be involved citing domestic violence as a private affair between men and women. Police officers may also lack the training or experience in dealing with cases of domestic abuse in relation with the law.

Sources: allAfrica.com, 2008; Human Rights Watch, 2003; IRIN Africa, 2008; Oxfam America, 2007.

Although a piece of legislation alone is not adequate to make HIV prevention or treatment happen – only adequate programs and services can – legislation can create an environment to empower people with knowledge, offer legal protection from stigma and discrimination, to enable behavior change, and access to HIV prevention, treatment and care without facing negative consequences.

HIV/AIDS has caused vast inequities and widespread stigmatization in the public health sector, especially among women (see Unit 2). The rights of those effected by HIV/AIDS need to be protected to address public health imperatives. By using law as an instrument of social change and protecting the rights of those infected and vulnerable to HIV/AIDS, an environment can be created whereby stigma, violence, and inequity can be reduced. This is widely accepted and established via a rights-based approach, which

promotes several inter-related rights, including informed consent to testing, the guarantee of confidentiality, non-discrimination, and access to treatment. The rights-based approach necessitates the creation of a legal environment that protects the rights of individuals affected by HIV/AIDS through the enunciation of legislation that guarantees such protection (*HIV/AIDS legislation: an opportunity for health care reform*, IJME, 2007).

International Guidelines on HIV/AIDS and Human Rights - A Key Legislative Tool for Parliamentarians

The *International Guidelines on HIV/AIDS and Human Rights* were developed to meet the needs of governments and to offer guidance on how to best promote, protect and fulfill human rights in the context of the HIV epidemic, both in terms of legislation and practice.

In 1996, United Nations Centre for Human Rights (UNCHR) and the Joint United Nations Program on HIV/AIDS (UNAIDS) invited thirty-five experts in the field of HIV/AIDS and human rights to an International Consultation on HIV/AIDS and Human Rights in Geneva. This Consultation brought together government officials and staff of national AIDS programmes, people living with HIV/AIDS (PLWHA), human rights activists, academics, representatives of regional and national networks on ethics, law, human rights and HIV, and representatives of United Nations bodies and agencies, non-governmental organizations and AIDS service organizations (ASOs).

The result was the creation of the *International Guidelines on HIV/AIDS and Human Rights*, which was published by the Office of the High Commissioner on Human Rights (OHCHR) and UNAIDS in 1998 and contains twelve principal guidelines (see Box 2), along with related commentary and recommendations for implementation. In 2002, some revisions of the Guidelines took place to better reflect advances in HIV-related treatment and antiretroviral medication, the global disparity in access to treatment, and the political and legal developments that had taken place with regard to treatment.

Box 2

OHCHR & UNAIDS Guidelines on HIV/AIDS and Human Rights

The Guidelines consist of 12 guidance points, each describing appropriate legislative and policy responses necessary for an effective response to the pandemic:

Guideline 1: States should establish an effective national framework for their response to HIV, which ensures a coordinated, participatory, transparent and accountable approach, integrating HIV policy and program responsibilities across all branches of government.

Guideline 2: States should ensure, through political and financial support, that community consultation occurs in all phases of HIV policy design, program implementation and evaluation and that community organizations are enabled to carry out their activities, including in the field of ethics, law and human rights, effectively.

Guideline 3: States should review and reform public health laws to ensure that they adequately address public health issues raised by HIV, that their provisions applicable to casually transmitted diseases are not inappropriately applied to HIV and that they are consistent with international human rights obligations.

Guideline 4: States should review and reform criminal laws and correctional systems to ensure that they are consistent with international human rights obligations and are not misused in the context of HIV or targeted against vulnerable groups.

Guideline 5: States should enact or strengthen anti-discrimination and other protective laws that protect vulnerable groups, people living with HIV and people with disabilities from discrimination in both the public and private sectors, ensure privacy and confidentiality and ethics in research involving human subjects, emphasize education and conciliation and provide for speedy and effective administrative and civil remedies.

Guideline 6 (revised in 2002): States should enact legislation to provide for the regulation of HIV-related goods, services and information, so as to ensure widespread availability of quality prevention measures and services, adequate HIV prevention and care information, and safe and effective medication at an affordable price.

States should also take measures necessary to ensure for all persons, on a sustained and equal basis, the availability of quality goods, services and information for HIV prevention, treatment, care and support, including antiretroviral and other safe and effective medicines, diagnostics and related technologies for preventative, curative and palliative care of HIV and related opportunistic infections and conditions.

States should take such measures at both the domestic and international levels, with particular attention to vulnerable individuals and populations.

Guideline 7: States should implement and support legal support services that will educate people affected by HIV about their rights, provide free legal services to enforce those rights, develop expertise on HIV-related legal issues and utilize means of protection in addition to the courts, such as offices of ministries of justice, ombudspersons, health complaint units and human rights commissions.

Guideline 8: States, in collaboration with and through the community, should promote a supportive and enabling environment for women, children and other vulnerable groups by

addressing underlying prejudices and inequalities through community dialogue, specially designed social and health services and support to community groups.

Guideline 9: States should promote the wide and ongoing distribution of creative education, training and media programs explicitly designed to change attitudes of discrimination and stigmatization associated with HIV to understanding and acceptance.

Guideline 10: States should ensure that Government and the private sector develop codes of conduct regard HIV issues that translate into human rights principles into codes of professional responsibility and practice, with accompanying mechanisms to implement and enforce these codes.

Guideline 11: States should ensure monitoring and enforcement mechanisms to guarantee the protection of -related human rights, including those of people living with HIV, their families and communities

Guideline 12: States should cooperate through all relevant programs and agencies of the United Nations system, including UNAIDS, to share knowledge and experience concerning HIV-related human rights issues and should ensure effective mechanisms to protection human rights in the context of HIV at an international level.

Source: OHCHR, 2006

Since the original publication and revision of the Guidelines, several significant developments have taken place in the right to health and access to HIV-related prevention, treatment, care and support, including important advances in access to antiretroviral therapy. An increased human rights-based approach is encouraged. Other global initiatives to halt and reverse the epidemic were launched during the 2005 World Summit Outcome, where the goal of universal access to treatment for all who need it by 2010 was set, which was also affirmed by *The Political Declaration on HIV/AIDS* in 2006 (see Unit 3).

The Guidelines were once again consolidated in 2006, and continues to provide important guidance to governments, parliaments, international organizations, non-governmental organizations and civil society groups on the development and implementation of effective national strategies for combating HIV/AIDS.

Legislative Review and Human Rights

As outlined above, included in the Guidelines are topics that should be addressed in national legislation to ensure that human rights are protected within the context of

HIV/AIDS. The following are **recommended topics for legislative review** based on the Guidelines:

- Discrimination against vulnerable groups in the workplace, schools and health care facilities;
- Equal access to health care;
- Voluntary testing and informed consent in HIV testing;
- Confidentiality of medical information;
- Partner notification of HIV status;
- Regulation of blood-safety standards;
- Regulation of HIV-related goods and services;
- Intentional exposure or transmission of HIV;
- Regulation of sex industry;
- HIV prevention and care services in prisons;
- Gender equality with respect to property rights and marital relations;
- Protection against sexual violence;
- Children's rights with respect to sexual abuse and HIV education, testing, and prevention;
- Care and support of orphans;
- Protection of rights of human participants in HIV/AIDS research.

The Importance of the Guidelines for Parliamentarians

The *International Guidelines* were primarily developed as a tool for parliamentarians and policymakers since they are responsible for drafting, reviewing and enacting legislation. Parliamentarians can assist with the implementation of the Guidelines by:

- Raising awareness among their peers about the Guidelines at regional, national and local levels to encourage dissemination, acceptance and implementation;
- Disseminating the Guidelines among other relevant partners and by developing action plans for monitoring and implementation of priority issues;
- Investigating government commitments and compliance with the Guidelines and by submitting the findings to Parliament;

- Legislating according to the guidelines by reviewing, amending and improving legislation to reflect Guideline recommendations.

The Guidelines offer specific benchmarks to implement and measure performance in creating an effective rights-based response to the epidemic. The *International Guidelines on HIV/AIDS and Human Rights* reinforce the obligations already contained in existing human rights declarations and conventions, including:

- *United Nations Charter*
- *Universal Declaration of Human Rights*
- *International Covenant on Economic, Social and Cultural Rights*
- *International Covenant on Civil and Political Rights*
- *Convention on the Elimination of all Forms of Racial Discrimination*
- *Convention on the Elimination of all Forms of Discrimination Against Women*
- *Convention on the Rights of the Child*
- *Convention Against Torture, and Other Cruel, Inhuman or Degrading Treatment or Punishment*
- *Various International Labor Organization conventions and recommendations*

For more information on these Declarations and Conventions, please refer to the internet resources at the end of this unit.

How do some of the relevant rights apply?

To empower rights-holders to claim their rights, to protect human dignity and to prevent the transmission of HIV, the following rights should be protected so that people will come forward for HIV information, education and means of protection, and will be supported to avoid risky behavior:

- **Non-discrimination:** protected against discrimination if seek help or are HIV+
- **Right to privacy:** protected against mandatory testing; HIV status kept confidential
- **Right to liberty and freedom of movement:** protected against imprisonment, segregation, or isolation in a special hospital ward

- **Right to education/information:** access to all HIV prevention education and information and sexual and reproductive health information and education
- **Right to health:** access to all health care prevention services, including for sexually transmitted infections, tuberculosis, voluntary counseling and testing, and to male and female condoms

Depending on the legal and social situation and the nature of the epidemic in country, some groups may be more vulnerable to infection and impact because of their legal status or lack of human rights protection, e.g. women, children, minorities, indigenous people, poor people, migrant-workers, refugees, sex workers, people who use drugs, men having sex with men, and prisoners.

These groups should have equal access to HIV prevention information, education, and commodities, and to HIV care, support and anti-retroviral treatment; should not be subject to sexual violence or coercion, where applicable; and should be able to participate in the formulation and implementation of HIV and AIDS policies that affect them.

- **Non-discrimination/equality before the law:** same access as others to services
- **Rights to education and health:** same access to HIV prevention education and information, and health care services, including STI services and condoms
- **Liberty, security of person and freedom from cruel, inhuman and degrading treatment:** freedom from violence, including sexual violence, freedom from mandatory testing
- **Right to participate in public life:** participation in the formulation and implementation of HIV policy

For those living with HIV or otherwise affected by it, the following rights should be protected:

- **Non-discrimination and equality before the law:** right not to be mistreated on the basis of health status, i.e. HIV status

- **Right to health:** right not to be denied health care/treatment on the basis of HIV status
- **Right to liberty and security of person:** right not to be arrested and imprisoned on the basis of HIV status
- **Right to marry and found a family,** regardless of HIV status
- **Right to education:** right not to be thrown out of school on the basis of HIV status
- **Right to work:** right not to be fired on the basis of HIV status
- **Right to social security, assistance and welfare:** right not to be denied these benefits on the basis of HIV status
- **Right to freedom of movement,** regardless of HIV status
- **Right to seek and enjoy asylum,** regardless of HIV status

(Source: www.unaids.org/en/PolicyAndPractice/HumanRights/default.asp)

Legislation on HIV/AIDS

As indicated above, the legislative requirements to effectively respond to HIV/AIDS are numerous and touch on several areas of the law. Considering HIV legislation dealing with human rights, criminal law, labor, public health, and marriage and taxation laws are essential to protecting the rights of people living with HIV/AIDS and ensuring strong prevention, treatment and care programs.

National intellectual property legislation is also required to ensure that the World Trade Organization Agreement on Trade-Related Aspects of Intellectual Property (TRIPS Agreement). However, in many cases this legislation needs to be reformed in order to adequately meet treatment requirements nationally.

Briefly, TRIPS are monitored by the World Trade Organization (WTO), and protect ideas and knowledge, including medicines and technology by giving sole ownership to the creator. The justification of such TRIPS is to stimulate incentive for invention and innovation. However, TRIPS have become controversial in the realm of HIV treatment, and TRIPS often prevent the production of generic or low-cost antiretrovirals for use in the developing world, thus creating a barrier to access – an issue discussed further in the latter half of this unit.

In general, legislation has proven to be insufficient to protect citizen's rights in relation to HIV/AIDS issues. Many countries have enacted select legislation to deal with certain issues, such as workplace discrimination, and most have enacted a national AIDS policy. Such a policy can provide an operating framework for the implementation of prevention, treatment, care and support programs addressing the epidemic. They can include principles on Human Rights for all, in particular the rights of people living with HIV/AIDS (PLWHA), as well as strategies on how to reduce vulnerability to HIV/AIDS for specific groups. In addition, a country's policy on HIV/AIDS can be a useful guide to domestic and international resource allocations for specific programs.

Box 3

The National Policy on HIV/AIDS in Botswana

The first national policy on HIV/AIDS in Botswana was developed in 1992 and was revised in 1998 in order to keep pace with developments. The HIV/AIDS policy emphasizes a multisectoral approach to the epidemic and an international Human Rights approach for addressing stigma and discrimination against PLWHA.

The key elements of the National AIDS Policy are the following: prevention of transmission of HIV/AIDS and sexually transmitted infections (STIs); mobilization of all sectors and of all communities for HIV/AIDS prevention and care; provision of care and support for the infected and/or affected; and education of the socio-economic consequences of HIV/AIDS and STIs.

The policy advocates for the involvement of all government Ministries at policy and operational levels, as well as non-governmental organizations (NGOs), community based organizations (CBOs), the private sector, parastatals, the United Nations and other development partners as stakeholders in the HIV/AIDS epidemic. The Office of the President and each Ministry has clearly defined roles in the policy. The policy also spells out the ethical and legal implications of HIV/AIDS, including those related to testing confidentiality, and outlines how programs and activities will be coordinated through the National Aids Council.

Source: *An Audit of HIV/AIDS Policies, 2004*

Laws to enshrine the right to education for boys and girls, legislation on criminalizing domestic violence and abuse, as well as legislation to provide women with equal inheritance are also important areas of concern for protecting the rights of those affected by HIV (See Unit 10). Ultimately, the presence of national AIDS policies without effective legal frameworks to enforce them is problematic. Several countries have taken steps to create national policies without developing specific legislation on HIV/AIDS.

Legislation provides a legally binding foundation with procedural, institutional and other accountability mechanisms to ensure the proper implementation of HIV/AIDS policies and programs.

While legislation in a number of sectors is required to effectively respond to the pandemic, there is also a general agreement that using a rights-based approach to develop legislation is the most comprehensive method to recognize and address societal vulnerability to HIV/AIDS and not simply individual risk behavior. Addressing HIV/AIDS from a human rights lens ensures that legislation is developed to protect the rights of people living with HIV/AIDS but also the disempowered populations that are more at risk of infection or affected by the impacts of the disease, groups such as women, children, men who have sex with men, injecting drug users, prisoners, sex workers and migrant workers.

Human Rights and AIDS

The following are key human rights and examples of their specific application in the HIV/AIDS context:

1. **Nondiscrimination and equality before the law** Eliminating discrimination against people living with HIV/AIDS in the areas of health care, employment, education, immigration, international travel, housing and social security;
2. **Health** Ensuring equal and adequate access to the means of prevention, treatment and care, such as for vulnerable populations with traditionally lower social and legal status (women and children);
3. **Privacy (both informational and physical)** Ensuring confidentiality of HIV test results, allowing disclosure at the discretion of the patient, and prohibiting mandatory or compulsory testing;
4. **Education and information** Ensuring equal and adequate access to prevention education and information such as targeted material for ethnic minorities;
5. **Freedom from inhuman, degrading treatment or punishment** Prohibiting automatic isolation of HIV-positive prisoners, as well as prohibiting the prosecution of HIV infected individuals for the “willful transmission of HIV”;

6. **Autonomy, liberty and security of the person** Prohibiting HIV testing or research without informed consent and prohibiting detention or quarantine solely on the basis of HIV status;
7. **Sharing in scientific advancement and its benefits** Ensuring equal and adequate access to safe blood supply and universal infection control protocols or treatment drugs;
8. **Work** Prohibiting dismissal of staff solely on the basis of their HIV status;
9. **Freedom of expression, assembly and association** Ensuring availability of registration of groups of people living with HIV/AIDS, such as sex workers or men who have sex with men;
10. **Participation in political and cultural life** Ensuring the participation of persons living with HIV/AIDS in the formulation, implementation and evaluation of policy;
11. **Marry and found a family** Prohibiting mandatory premarital testing and coerced abortions or sterilizations among HIV-positive patients.

Source: *Handbook for Legislators on HIV/AIDS, Law and Human Rights (1999)*

Legislative Implications

Legislative Implications for HIV Testing and Counseling

It is recognized that access to voluntary, affordable and high-quality HIV testing and counseling (VCT) is crucial to the successful response to HIV, and should be guaranteed under the implementation of human rights-based legislation. However in many countries access to HIV testing and counseling remains limited and many people, both in the developing and developed world, are not aware of their HIV status. When looking to improve access to testing and counseling, certain legislative and policy considerations are required such as conditions of informed consent and confidentiality.

In the case of HIV testing, informed consent is a legal condition whereby a person has given consent to being tested based upon an appreciation and understanding of the facts and implications of that action. Not only do individuals have the right to know that they are being tested for HIV, they also have the right to be offered pre- and post test

counseling regardless of the test result. HIV testing should never be forced, coerced, or clandestine. Furthermore, test results are to be kept confidential, and revealed only to the patient being tested. As has been discussed in previous units, the implications for unauthorized disclosure of HIV status can result in the abuse, abandonment, or stigmatization faced by the patient and may discourage individuals from seeking testing and counseling even when they fear HIV infection.

When the requirements of informed consent and confidentiality are met through the implementation of firm legislation, individuals will feel compelled to enter into the health care system knowing that their rights are protected, thus improving access and adherence to treatment and decrease the chance of the patient passing HIV on to others unknowingly.

Box 3

Strict Confidentiality Law in the Philippines

The Philippines offers an example of HIV legislation developed to protect the HIV positive population. In that country, the law applies strong confidentiality provisions to protect the privacy of HIV data. Confidentiality protection must be upheld for medical records 'obtained by health professionals, health instructors, co-workers, employers, recruitment agencies, insurance companies, data encoders, and other custodians of said record, file or data'.

Those who violate medical confidentiality risk imprisonment for anytime between six months to four years and other sanctions such as fines and loss of license to practice medicine. Confidential HIV test information may only be released to the person who was tested, the parent of a minor who was tested, a legal guardian of the tested person, those authorized to receive HIV information through the HIV reporting system in the government, and judges.

Source: *Legal Aspects of HIV/AIDS: A Guide for Policy and Law Reform, 2007*
(Additional examples of HIV legislation are available in this document)

It is also important for parliamentarians to know that according to the *International Guidelines*, public health legislation should ensure:

- That HIV testing of individuals should only be performed with the specific informed consent of that individual;
- Whenever possible, that pre- and post-test counseling be provided in all cases;
- That HIV and AIDS cases reported to public health authorities for epidemiological purposes are subject to strict rules of data protection and confidentiality;

- That information relative to the HIV status of an individual must be protected from unauthorized collection, use or disclosure in the healthcare and other settings and that the use of HIV-related information required informed consent.

Parliamentarians have a responsibility to ensure that legislation be developed or reformed to meet these recommendations. This legislation is not only important to the general population, but to those in concentrated epidemics, or traditionally criminalized and highly vulnerable groups. Model laws can be appropriately applied when reforming legislation which traditionally criminalized populations vulnerable to HIV infection or discrimination.

Model laws are designed to inform and assist policy-makers and advocates as they approach the task of reforming or making laws to meet the legal challenges posed by the HIV epidemic. Typically model laws attempt to establish a clear legal framework for addressing HIV/AIDS issues among traditionally criminalized groups, such as injecting drug user, sex workers, or men who have sex with men. Model laws should be developed in line with the states' human rights obligations and it is important to ensure that these model laws do not restrict the rights of certain groups of the population to access prevention, treatment care and support in relation to HIV/AIDS.

Box 4

Problematic Legislation on HIV Testing – Misuse of “Model Laws”

In recent years, the *Model Legislation on HIV/AIDS for West and Central Africa*, also known as the *N'Djamena Model Law*, was drafted by AWARE-HIV/AIDS (Action for the West Africa Region). Generally, this initiative has been useful in terms of promoting the need for national HIV legislation and raising awareness about the role of legislators and government policy-makers in the fight against HIV/AIDS. However, the model law itself has been heavily criticized for failing to protect human rights and gender equality – a key component of developing effective model law.

Specifically:

- The N'Djamena “model law” contains language that could restrict HIV prevention educational activities.
- In contradiction to the *International Guidelines*, the “model law” allows mandatory HIV testing in situations such as where pregnant women go for a medical check-up, or “to solve a

matrimonial conflict.” Mandatory testing for pregnant women jeopardizes women’s health and lives by discouraging them from seeking pregnancy related care.

- The “model law” imposes a blanket duty on health care practitioners to disclose the HIV status of their patients to their patients’ spouses or sexual partners, regardless of the actual risk of transmission. The law contains no provisions to ensure that the person living with HIV be given advance warning of such notification, nor any means to prevent violence or abandonment that may be a direct result of such involuntary disclosure. This provision has particular implications for women who bear the brunt of intimate partner violence.
- The “model law” criminalizes “the willful transmission of HIV”, and defines HIV transmission to be transmission of the virus “by any means”. This broad language could impose criminal penalties even on individuals who practice safer sex and/or disclose their HIV status to their sexual partners, or on mothers who transmit HIV to their children, either in utero or during labor and delivery.

The N'Djamena “model law” has been promoted as a template for legislation and at least seven countries in West Africa have used it as the basis for their national HIV laws, while at least six others are in the process of developing laws using the same model. It is therefore critical that it be revised so that it provides parliamentarians with a resource that reflects international human rights principles and the United Nations Office of the High Commissioner for Human Rights (OHCHR) *International Guidelines*. Specifically, the law should be revised to include provisions that specifically protect the rights of women, prisoners, and other vulnerable populations as well as to amend existing provisions on:

- Education on HIV and AIDS in schools;
- Mandatory HIV testing;
- Partner notification;
- Discrimination;
- Criminalization of transmission

Several organizations such as the Canadian Legal HIV/AIDS Network with support from the UNAIDS Regional Office for West Africa have been working with parliamentarians and officials from the region to provide technical assistance and recommendations to revise and amend legislation to respect international human rights law and the *International Guidelines on HIV/AIDS and Human Rights*.

Source: *HIV/AIDS Policy and Law Review*, Canadian HIV/AIDS Legal Network, 2007

Legislative Implications for Stigma and Discrimination

Stigma and discrimination cause HIV to be viewed through a “moral” or judgmental lens, as opposed to a public health or multisectoral issue. As a result, people living with the virus are constantly subject to abuse and prejudice, they are dismissed from jobs, forced out of homes, disowned by families and friends and some have even been killed because of their HIV status. Stigma and discrimination are detrimental to efforts to combat the disease since fear of discrimination forces people to keep silent about their status, or even worse still, to refuse testing.

While parliamentarians have a role to play in speaking out publicly against stigma and discrimination in order to change the mindset and the attitudes surrounding HIV, as legislators they can also enact and enforce legislation and regulations to eliminate all forms of discrimination against people living with HIV/AIDS and members of vulnerable groups.

In the *Declaration of Commitment* (2001) UN member states committed themselves to adopt legislation to prevent stigma and discrimination against people living with HIV. At the beginning of 2008, *Country Progress Reports* from 147 countries were submitted to UNAIDS, which together represent the most comprehensive body of evidence ever assembled regarding the response to HIV in low, middle and high-income countries (see Unit 3).

Although these reports have revealed gains in the response to HIV/AIDS in many regions, these achievements can also be assessed for continuing work to be done.

Approximately 40% of all countries which submitted progress reports, and almost half of those in sub-Saharan Africa failed to meet the commitment specific to the issue of stigma and discrimination.

In order to meet international commitments and to secure policy and legal change to eliminate discrimination, **parliamentarians should:**

- Strengthen legislation, regulations and other measures to eliminate all forms of discrimination against people living with HIV;
- Review labor laws to ensure that they address the specific issues of HIV in employment and vocational training, consistent with the principles contained in the *ILO Code of Practice on HIV/AIDS and the World of Work*;
- Review, amend or enact confidentiality and privacy laws that adequately address HIV;
- Recommend and oversee the training of relevant officials, including labor court judges and industrial tribunal magistrates who hear cases of employment-related discrimination (*Taking Action Against HIV*, 2007).

Below is a useful checklist, which serves as a model for evaluating and reviewing various legislation needed for confidentiality and privacy protection. Additional checklists on other HIV legislation are available in the *Taking Action Against HIV Handbook* and the *Handbook for Legislators on HIV/AIDS, Law and Human Rights*.

Box 5

Checklist of Components of Privacy Legislation

When drafting or reviewing legislation to adequately cover HIV, the following issues should be considered:

1. Does the legislation provide for general privacy or confidentiality protection for medical and/or personal information, widely defined to include HIV-related data?
2. Does the legislation prohibit unauthorized use and disclosure of such data?
3. Does it provide for confidentiality of HIV-related personal information at the workplace?
4. Does the legislation provide for the subject of the information to have access to his or her own records and the right to require that the data be accurate, relevant, complete and up to date?
5. Does other general or public health legislation provide for the right of HIV-positive people to have their privacy and/or identify protected in legal proceedings (e.g. closed hearings and/or use of pseudonyms)?
6. Does public health legislation provide for adequate privacy protections (e.g. use of coded rather than nominal data) were reporting cases of HIV or AIDS to public health authorities for epidemiological purposes?

Source: *Taking Action Against HIV, 2007*

Legislative Implications for Prevention

Despite international and national efforts, new HIV infections are still on the rise and the need for strong prevention programs remains urgent and critical.

From a legislative perspective, parliamentarians have a role to play in order to review and reform legal frameworks to eliminate barriers to prevention. Examples include the following measures:

- Enacting laws to **eliminate of gender-based inequalities** that fuel the epidemic;

- Ensuring that health care policies are **free of discrimination** and that services are offered equally to all members of society including vulnerable groups;
- **Reviewing any laws** or regulations that impede on a) the distribution of sexual health education and information; b) the provision of condoms, sterile injecting equipment and other harm reduction measures; c) work with members of vulnerable populations, including sex workers, MSM, injecting drug users and prisoners;
- Reforming criminal laws and policies **regulating correctional services** to ensure that such facilities do not use ineffectual or harmful methods to control HIV and that the rights of people living with HIV or populations at risk are not discriminated against.

Box 6

Prevention of Mother to Child Transmission of HIV (PMTCT)

A pregnant HIV positive woman can transmit the virus to her unborn child in the womb, during childbirth, as well as when breastfeeding. Mother-to-child transmission (MTCT) is the highest source of infection in children under 10. However, significant advances in the use of antiretroviral drugs, particularly given immediately before and after delivery, have significantly reduced the risk of transmission.

The effective use of antiretroviral drugs in controlling MTCT provides a strong rationale for widespread testing of pregnant women. However, most policymakers and healthcare practitioners are opposed to mandatory HIV testing for pregnant women. Mandatory testing is not only seen as a breach of an individual's independence and autonomy but officials fear it could deter many women from seeking medical care during pregnancy for fear of stigma and discrimination when HIV results are known.

Some countries do, however, impose mandatory screening of newborns if the mother does not consent to an HIV test. This action is controversial, as the rights of the child are often in competition with the rights of the mother, this should not be an either/or approach.

In order to reconcile the needs of both parties, women need to be offered appropriate pre- and post-test counseling so that the risk of HIV infection and consequences to themselves and their newborns are fully understood. It is also important to make clear that test results will not negatively impact the quality of care given to the mother or her child – especially if the result indicates HIV infection. Furthermore, test results must remain confidential and disclosed at the discretion of the patient, to avoid cases of abuse or abandonment which may occur.

Source: *Legal Aspects of HIV/AIDS – A Guide for Policy and Law Reform, 2007*

Legislative Implications for Access to Treatment

One of the largest impediments to treatment in low and middle-income countries is access to affordable medication. Impacting this barrier is the issue of patent laws, which prohibit the manufacturing of low cost generic drugs, often sold in the developing world (see Unit 2).

Although it is recognized that patents are valuable for creating incentive for innovation and invention, in a state of crisis, including a health crisis, preexisting technologies must be readily accessible to meet the immediate needs of those who are infected. This is reflexive not only of the 2001 Doha Declaration on the TRIPS Agreement and Public Health, but also maintains the spirit of best practice and information sharing outlined in many key international agreements.

Briefly, the Doha Declaration stipulates that TRIPS should not interfere with the rights of WTO Members to protect and maintain public health. With this in mind, the Doha Declaration outlines several “flexibilities” which often translate into the production or importation of generic drugs.

Parliamentarians can therefore take significant steps to remove trade barriers including:

- **Change national intellectual property legislation** to ensure that TRIPS flexibilities are incorporated into national laws and regulations;
- **Reform national patent laws** in developing countries, for example as in Brazil (see Unit 2), to allow national authorities the option of not providing patent protection in the pharmaceutical sector until 2016, as stipulated in the WTO Doha Declaration. This can be of great importance in high HIV prevalence countries where the provision of ARVs to all those in need can be very costly; and
- **Reform legislation and tax codes** to exempt HIV treatment commodities, including HIV medicines, and other essential medicines from all taxes and tariffs.

Box 7

TRIPS Agreement Waiver

In 2003, a WTO waiver was adopted to overcome the limitations of TRIPS that called for compulsory licenses to be authorized for the supply of the domestic market of the member granting the license. The system established under the waiver decision requires that compulsory licenses are granted in the exporting country and that notification is required to the importing country.

Various potential exporting countries (including Canada, China, the EU, India, the Netherlands and Norway) have implemented the 2003 WTO waiver decision in their legislation.

In Canada, the *Jean Chrétien Pledge to Africa Act* was the first such reform effort. It amends the country's Patent Act by adding a section on 'Use of Patents for International Humanitarian Purposes to Address Public Health Problems.'

The amendment is aimed at 'facilitating access to pharmaceutical products to address public health problems afflicting many developing and least-developed countries, especially those resulting from HIV/AIDS, tuberculosis, malaria and other epidemics.'

Source: *Legal Aspects of HIV/AIDS – A Guide for Policy and Law Reform, 2007*

Working with Civil Society on HIV/AIDS Legislation

Parliamentarians and parliamentary staff often lack the time and the resources to conduct the necessary research during the process of developing new legislation and policies, or when reviewing existing legislation. It is also important that parliamentarians have access to varying and independent sources of information to be able to make informed decisions. Civil society organizations and research institutes addressing HIV/AIDS from a legal perspective can prove to be a valuable resource in this regard. They can often provide examples of existing research in various areas, best practices and model legislation. Some organizations can also offer capacity building in these areas. Parliaments can involve the representatives of these organizations to provide advice and analysis on existing legislation and policies, for example through a public consultation process on a particular law or policy. They can also engage them to take a more active part in the development or review of this particular law or policy.

Box 8

Indian Parliamentarians Working with Civil Society to Develop HIV/AIDS Legislation

India provides a recent example of parliamentarians reaching out to experts within civil society to develop legislation on HIV/AIDS. A member of Parliament from the Indian Lok Sabha was instrumental in requesting that the Civil Society Organization (CSO), Lawyers Collective

HIV/AIDS Unit, prepare draft legislation to be presented to the Indian Parliament.

The Lawyers Collective undertook a comparative exercise to review legal developments regarding HIV in other countries and adapted these findings and best practices to the Indian context. The Lawyers Collective also conducted nationwide consultations on the draft legislation and invited witnesses from various sectors infected or affected by the epidemic. Findings and recommendations from the consultation process were then incorporated into the final draft bill.

The draft law has been under consideration by the Ministry of Law and Justice since 2006. It was accepted in the Health Ministry but the Ministry of Law and Justice has raised some concerns that have delayed the bill in parliament. Civil society is now calling on parliament to consider the bill urgently. The Indian Network for People Living with HIV/AIDS, along with several other NGOs and advocacy groups, are now campaigning publicly for Parliament to adopt the bill.

Source: www.lawyerscollective.org/content/draft-law-hiv

There are many organizations or initiatives focusing on the legal aspects of HIV/AIDS that could be used as expertise during the development or review of policies or legislation related to HIV/AIDS. Here follows some examples, but parliamentarians should try and identify relevant organizations in their own countries that could potentially perform this service.

- AIDS and Rights Alliance for Southern Africa (ARASA)
- AIDS Law Project (South Africa)
- AIDS Law Unit of the Legal Assistance Centre (Namibia)
- AIDS Legal Network (South Africa)
- Botswana Network on Ethics, Law and HIV/AIDS (BONELA)
- Canadian HIV/AIDS Legal Network
- International HIV/AIDS Alliance
- Lawyers Collective (India)
- The UK Law and HIV/AIDS Project
- Uganda Network on Law, Ethics & HIV/AIDS (UGANET)
- Zambia AIDS Law Research & Advocacy Network (ZARAN)

Key Resources for Legislators:

UNAIDS and other partners recommend several documents that can be used as guidelines to draft or amend HIV-related legislation in accordance with international

legal norms and standards to ensure that the language used to enact the law does not allow human rights abuses. These documents include:

- *Handbook for Legislators on HIV/AIDS, Law and Human Rights* (1999);
- *The Political Declaration on HIV/AIDS* (2006);
- *The International Guidelines on Human Rights and HIV, consolidated version* (2006);
- *Taking Action Against HIV, Handbook for Parliamentarians* (2007);
- *Legal Aspects of HIV/AIDS: A Guide for Policy and Law Reform* (2007); and
- *UNAIDS Recommendations for Alternative Language in the Ndjamena Legislation on HIV* (2008)

Box 9

Legal Aspects of HIV/AIDS: A Guide for Policy and Law Reform

The World Bank released the publication *Legal Aspects of HIV/AIDS: A Guide for Policy and Law Reform* in September 2007. This document addresses HIV/AIDS from a multisectoral perspective. It covers 65 wide-ranging topics in a concise, accessible format, explaining how laws and regulations can either underpin or undermine public health programs and responsible personal behavior.

For example, laws relating to many areas of our lives - from intimate private conduct to international travel - can contribute to stigma, discrimination, and exclusion or, contrariwise, can avoid and help remedy these inequities. Thus, in order to create a supportive legal framework it is important that governments identify and address effectively any gaps or other problematic aspects of their legislation and regulatory systems, and this guide sets out to assist in this endeavor. Furthermore, the Guide recognizes that national governments can rely on, and should insist on, support from international and local organizations already working to fight against HIV/AIDS.

The Guide is comprised of 12 sections including:

1. Public Health Policies and Practices;
2. Discrimination;
3. Disclosure and Exposure;
4. Injecting Drug Use;
5. Sex Work;
6. Men Who Have Sex With Men;
7. Women;
8. Children;
9. Clinical Research;
10. Information;
11. Access to Medicines; and
12. World Bank Policies and Procedures

For each topic, the Guide summarizes the key legal or policy issues, provides relevant "practice

examples" (citing actual laws and regulations), and offers a selective list of references that may be consulted for more information. This can therefore be an invaluable resource for parliamentarians, policy makers, and other practitioners with an interest in countries' responses to HIV/AIDS and its review and use by parliamentarians is highly recommended.

Sources: <http://web.worldbank.org/WBSITE/EXTERNAL/TOPICS/EXTHEALTHNUTRITIONANDPOPULATION/EXTHIVAIDS/0,,contentMDK:21559860~pagePK:210058~piPK:210062~theSitePK:376471,00.html>

Unit 5: Questions

Please answer each of the following questions. If you are taking this course in a group you may then meet to discuss your answers.

1. Summarize the 12 International Guidelines on HIV/AIDS and Human Rights. Can you identify examples of legislation required to address the issues identified in the guidelines?
2. What HIV legislation currently exists in your country? Provide specific examples of rights-based legislation that protects people living with HIV.
3. What is the most recent legislation promulgated by your Parliament on HIV/AIDS? Are you aware of other legislation required to strengthen the legal framework on HIV/AIDS in your country?
4. What resources are available that help guide the development and evaluation of HIV/AIDS legislation?

Selected Bibliography:

An Audit of HIV/AIDS Policies: In Botswana, Lesotho, Mozambique, South Africa, Swaziland, and Zimbabwe, by Nompumelelo Zungu-Dirwayi, Social Aspects of HIV/AIDS and Health Research Program, 2004

Doha Declaration on TRIPS Agreement and Public Health, WTO, 2001

Handbook for Legislators on HIV/AIDS, Law and Human Rights, UNAIDS and IPU, 1999

HIV/AIDS Policy and Law Review 12(2/3), Canadian HIV/AIDS Legal Network, December 2007

HIV/AIDS legislation: an opportunity for health care reform, by Vivek Divan and Kajal Bhardwaj, IJME, 2007

International Guidelines on HIV/AIDS and Human Rights, 2006 Consolidated Version, OHCHR and UNAIDS, 2006

Legal Aspects of HIV/AIDS: A Guide for Policy and Law Reform, World Bank, 2007

Taking Action against HIV: Handbook for Parliamentarians, IPU, 2007

Uganda: Domestic Violence Worsens AIDS – Battered Women Face Greater Vulnerability to HIV, Human Rights Watch, 2003

Uganda: Poverty, wars, and alcohol perpetuate domestic violence, IRIN Africa, 2008

Zimbabwe Looks to New Domestic Violence Law, Oxfam America, 2007

Zimbabwe: "Most People Ignorant of Domestic Violence Law", allAfrica.com, 2008

Internet resources:

International Declarations and Conventions:

United Nations Charter:

www.un.org/aboutun/charter/

Universal Declaration of Human Rights

www.un.org/Overview/rights.html

Convention Against Torture, and Other Cruel, Inhuman or Degrading Treatment or Punishment:

www.unhchr.ch/html/menu3/b/h_cat39.htm

Convention on the Elimination of all Forms of Discrimination Against Women:

www.un.org/womenwatch/daw/cedaw/

Convention on the Elimination of all Forms of Racial Discrimination:

www.unhchr.ch/html/menu3/b/9.htm

Convention on the Rights of the Child:

www.unhchr.ch/html/menu3/b/k2crc.htm

International Covenant on Civil and Political Rights:

www.hrweb.org/legal/cpr.html

International Covenant on Economic, Social, and Cultural Rights:

www.unhchr.ch/html/menu3/b/a_cescr.htm

Declaration on Fundamental Principles and Rights at Work and other priority conventions:

www.ilo.org/global/What_we_do/InternationalLabourStandards/Introduction/ConventionandRecommendations/lang--en/index.htm

www.ilo.org/public/english/protection/trav/aids/code/languages/index.htm

Office of the High Commission for Human Rights:

www2.ohchr.org/english/issues/hiv/guidelines.htm

Human Rights and HIV

www.unaids.org/en/PolicyAndPractice/HumanRights/default.asp

Organizations working on legal aspects of HIV/AIDS:

AIDS and Rights Alliance for Southern Africa (ARASA)

www.arasa.info

AIDS Law Project (South Africa)

<http://alp.org.za/dedi20a.your-server.co.za/index.php>

AIDS Law Unit of the Legal Assistance Centre (Namibia)

www.lac.org.na/projects/alu/aluobjective.html

AIDS Legal Network (South Africa)

www.aln.org.za

Botswana Network on Ethics, Law and HIV/AIDS (BONELA)

www.bonela.org

Canadian HIV/AIDS Legal Network

www.aidslaw.ca

International HIV/AIDS Alliance

<http://www.aidsalliance.org/sw7189.asp>

Lawyers Collective (India)

www.lawyerscollective.org

The UK Law and HIV/AIDS Project

www.keele.ac.uk/research/lpj/Law_HIV-AIDSPROJECT

Uganda Network on Law, Ethics & HIV/AIDS (UGANET)

www.uganet.org

Zambia AIDS Law Research & Advocacy Network (ZARAN)

www.zaran.org

Suggestions for further reading:

HIV/AIDS and the Law, Black Sash and the Education and Training Unit, 2002

Human Rights Protected? Nine Southern African Country Reports on HIV, AIDS and the Law, by Frans Viljoen and Karen Steffiszyn (eds.), AIDS and Human Rights Law Research Unit, 2007

Model Law on HIV in Southern Africa – Position Paper, SADC Parliamentary Forum, 2007

Model Law on HIV in Southern Africa (Draft) - SADC Parliamentary Forum, 2008

Political Declaration on HIV and AIDS (2006), universal access process, and civil society engagement, Issue Paper, UNAIDS Reference Group on HIV and Human Rights, February 2007

The UNGASS Declaration of Commitment on HIV/AIDS: A Review of Legislation in Six Southern African Countries, Canadian HIV/AIDS Policy & Law Review, Vol. 8, Number 1, April 2003