

TAKING ACTION AGAINST HIV AND AIDS



INTER-PARLIAMENTARY UNION



UNITED NATIONS
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Taking action against HIV and AIDS

A handbook for parliamentarians

Handbook for parliamentarians N° 15/2007



INTER-PARLIAMENTARY UNION



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Acronyms

AIDS	Acquired immunodeficiency syndrome
APPG	All-Party Parliamentary Group
ART	Antiretroviral treatment (or therapy)
ASAP	AIDS Strategy and Action Plan (of The World Bank)
ASO	AIDS service organization
AWEPA	Association of European Parliamentarians for Africa
CAPAH	Coalition of African Parliamentarians Against HIV and AIDS
CEDAW	Convention on the Elimination of all forms of Discrimination Against Women
CEGAA	Centre for Economic Governance and AIDS in Africa
CRC	Convention on the Rights of the Child
CSHA	Canadian Strategy on HIV/AIDS
CSO	Civil society organization
DAC	Development Assistance Committee
DDA	Disability Discrimination Act (United Kingdom)
HIPC	Heavily indebted poor country
HIV	Human immunodeficiency virus
ICCPR	International Covenant on Civil and Political Rights
ICESCR	International Covenant on Economic, Social and Cultural Rights
IDASA	Institute for Democracy in South Africa
IDP	Internally displaced person
IDU	Injecting drug user
ILO	International Labour Organization
IMF	International Monetary Fund
INCB	International Narcotics Control Board
IOM	International Organization for Migration
IPU	Inter-Parliamentary Union
LDC	Least developed country
MDGs	Millennium Development Goals
MP	Member of parliament
MSM	Men who have sex with men
MTCT	Mother-to-child transmission (of HIV)
NACO	National AIDS Control Organisation (India)

NGO	Nongovernmental organization
ODA	Official development assistance
OECD	Organisation for Economic Cooperation and Development
OECS	Organisation of Eastern Caribbean States
OHCHR	Office of the United Nations High Commissioner for Human Rights
PEP	Post-exposure prophylaxis
PFA	All-Party Parliamentarians' Forum on HIV/AIDS (India)
PITC	Provider-initiated testing and counselling
PMTCT	Prevention of mother-to-child transmission (of HIV)
PPAPD	Pacific Parliamentary Assembly on Population and Development
PRSP	Poverty reduction strategy paper
STD	Sexually transmitted disease
STI	Sexually transmitted infection
TAPAC	Tanzanian Parliamentarians AIDS Coalition
TB	Tuberculosis
TRIPS	(Agreement on) Trade-Related Aspects of Intellectual Property Rights
UDHR	Universal Declaration of Human Rights
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNDCP	United Nations International Drug Control Programme
UNDP	United Nations Development Programme
UNESCO	United Nations Educational, Scientific and Cultural Organization
UNFPA	United Nations Population Fund
UNGASS	United Nations General Assembly Special Session
UNHCR	Office of the United Nations High Commissioner for Refugees
UNICEF	United Nations Children's Fund
UNODC	United Nations Office on Drugs and Crime
VCT	Voluntary counselling and testing
WFP	World Food Programme
WHO	World Health Organization
WTO	World Trade Organization

Foreword

This Handbook is both a call to action for parliamentary leadership and a reference book to which parliamentarians and their staff may turn for information and guidance on specific issues of importance in the response to HIV. The Handbook provides many illustrations of good practice by legislatures and gives examples of leadership by individual parliamentarians. It pays tribute to the personal and political courage of parliamentarians all around the world who have spoken out about the gravity and exceptional nature of HIV and about how their own lives have been affected by the epidemic. Members of parliament have mobilized resources to help achieve universal access to comprehensive HIV services, and they have helped to defend the human rights of people living with HIV and key vulnerable groups – women and girls, children orphaned or affected by AIDS, sex workers, people who use drugs, men who have sex with men, and prisoners – whose active engagement is central to a successful AIDS response.

We now call upon parliaments to do even more to help achieve universal access to HIV prevention and treatment, care and support, including for members of key groups at higher risk of HIV. As part of this endeavour, parliaments must establish a system of governance based on protecting, promoting and fulfilling the human rights of all people, including those who are frequently stigmatized and discriminated against by mainstream society.

This Handbook emphasizes the importance of human rights because they are so essential to the response to AIDS. Parliaments have a central role to play in promulgating and overseeing the enforcement of national laws for an approach to HIV that is informed by evidence and by the *International Guidelines on HIV/AIDS and Human Rights*.

The United Nations General Assembly, in its June 2006 *Political Declaration on HIV/AIDS*, emphasized that legal, regulatory and political barriers in countries continue to block peoples' access to effective prevention programmes, such as substitution therapy for opioid dependence, widespread dissemination of sex education and information, and access to condoms (including for sexually active young people). Parliaments can enact legislation to remove these barriers. Similarly, parliamentarians can ensure that they pass national laws that allow their governments to use existing global trade rules (such as the World Trade Organization's *Agreement on Trade-related Aspects of Intellectual*

Property Rights (TRIPS) and the Doha Declaration on the TRIPS Agreement and Public Health) to ensure access to affordable HIV medicines and other essential pharmaceuticals. At the same time, parliamentarians can promote the repeal of laws (such as those mandating HIV testing for certain populations) that are prejudiced, ineffective in dealing with the epidemic and further stigmatize at-risk populations.

The global AIDS epidemic has become one of the world's make-or-break social, economic, development and humanitarian crises, no longer solely a public health problem. In 2006, 4.3 million people were newly infected with HIV and nearly 3 million people died of AIDS. The vast majority of these HIV infections and AIDS deaths could have been prevented. Moreover, in recent years, the epidemic has become increasingly "feminized". Women continue to be subject to inequality and violence in their homes and communities – in general and as a result of AIDS – and this driver of the epidemic remains far from being addressed. Parliaments and their members can play a leading role in helping to reverse these trends and creating the conditions that will enable us to end the AIDS epidemic.

This Handbook is the result of a long-standing, close collaboration in the response to the challenge of HIV between the Inter-Parliamentary Union, UNDP (as a UNAIDS cosponsoring agency with the lead roles in governance and human rights), and UNAIDS as a whole. We hope that this Handbook will inspire and help parliaments and parliamentarians everywhere to intensify evidence-informed political leadership and to exercise fully their legislative, budgetary and oversight powers to tackle HIV in their communities and countries.

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Preface

Parliaments have always been confronted with problems affecting the welfare of society, tackling questions that cut across the fields of public health and human rights. However, the AIDS epidemic has consistently placed new and increasingly complicated demands on the world's lawmakers. In facing this challenge, parliamentarians have sought to learn from each other, working through international networks and exchanging ideas and practices in the development of legislation that is sensitive, informed and enforceable. As the focal point for worldwide parliamentary dialogue, the Inter-Parliamentary Union (IPU) seeks to bring cohesion to this sometimes fragmented process in order to facilitate a global exchange of information and to keep the AIDS epidemic high on every parliament's legislative agenda.

To further this objective, the IPU Advisory Group on HIV/AIDS was established in 2006. It is a small group of legislators who, in their home parliaments, are leaders in addressing AIDS and related issues. The Group's mission is to conduct field visits to learn lessons from national responses that can be shared with the wider parliamentary community; to provide guidance to the world's parliaments on the implementation of international commitments on AIDS; and to organize global inter-parliamentary conferences on AIDS - the first scheduled in Manila at the end of 2007. The Group also helps design information and training materials for parliamentarians worldwide, and this Handbook bears eloquent witness to the value of that work.

Like no other contemporary crisis, the AIDS epidemic impinges upon a complex array of social, economic and humanitarian concerns. In the deadly havoc wrought by the disease, assumptions about human development patterns have been turned on their heads. Covering the full range of issues in a single volume has proven immensely challenging, and this Handbook is testament to the talents and dedication of its author, Ralf Jürgens. I would also like to express our deepest gratitude to our partners at UNDP and UNAIDS, whose advice and knowledge have been invaluable. I am convinced that this book will be tremendously useful to our parliaments for many years to come.

Dr Elioda Tumwesigye, MP,
Chairman of the IPU Advisory Group on HIV/AIDS

Executive summary

Why parliamentarians play a key role in the response to HIV and AIDS

HIV is one of the most serious threats facing the world at the beginning of the 21st century, and parliamentarians have a major role to play in addressing the epidemic.

- As representatives of the people, parliamentarians can reflect the voices and concerns of *all people*, including those living with or affected by HIV and members of key groups at higher risk, such as marginalized communities.
- As opinion-leaders and decision-makers, parliamentarians can promote respect among their constituents for people living with HIV, and can encourage informed debate on issues related to HIV, based on scientific evidence and supportive cultural values – not popular myths, political ideologies, prejudicial beliefs or harmful cultural practices. Parliamentarians can help the public understand that, even though HIV provokes prejudices and misconceptions because of its relationship to blood, sex, drug use, sickness and other often sensitive subjects, it can be effectively prevented and treated, like other diseases, if these prejudices and misconceptions are overcome.
- As lawmakers, parliamentarians can design, adopt and oversee the implementation of legislation that protects human rights and advances (rather than hinders) effective HIV prevention, care and treatment programmes. Whether such legislation takes the form of constitutional amendments to prohibit discrimination against people living with HIV (or those most vulnerable to infection), laws to ensure the rights of school-age children to be educated on how to protect themselves, or amendments to national intellectual property legislation to ensure that TRIPS flexibilities are incorporated into national laws (to name just a few areas of concern), legislators are critical to ensuring the effectiveness of responses to the epidemic.
- As overseers of government activity, parliamentarians can ensure that government commitments on HIV are respected.
- As overseers of national budget appropriations, parliamentarians can ensure that adequate and cost-effective funding is provided to both national and international AIDS programmes, and that funding is steered towards interventions informed by the best available evidence of effectiveness and based on fundamental human rights principles.

What this Handbook contains

The objective of this Handbook is to provide parliamentarians with the information they need in order to initiate and promote the evidence-informed and rights-based HIV response that is crucial to achieving universal access to HIV prevention, treatment, care and support for all. Particular attention is devoted to assisting parliamentarians in taking action and making decisions on HIV-related law and policy reform, by providing information on the critical role of human rights in the overall response to the epidemic. This has become even more important since governments – indeed, all United Nations Member States – have committed themselves (most recently in the 2006 *Political Declaration on HIV/AIDS*) to “overcoming legal, regulatory or other barriers that block access to effective HIV prevention, treatment, care and support, medicines, commodities and services”. Members of parliament have also made commitments to adopt a rights-based approach to HIV and to move swiftly to reform legislation to ensure that it advances effective HIV prevention, treatment, care and support. In particular, in a number of resolutions, the Assembly of the Inter-Parliamentary Union called upon parliaments and governments to ensure that their laws, policies and practices respect human rights in the context of HIV. However, in practice, in many countries, legislation continues to hinder, rather than advance, effective action against HIV.

To date, the parliamentary record on HIV legislation is mixed. Some parliaments have passed legislation that advances effective prevention, treatment and care programmes. Others have seen bills on HIV or related issues (such as domestic relations, gender-based violence, and discrimination) languish for years on the parliamentary agenda. Still others have passed legislation that fails to protect human rights or advance evidence-informed prevention and treatment, and instead authorizes coercive measures that have proven to be ineffective – such as, for example, mandatory or compulsory HIV testing of certain people or in certain situations.

In Part I (Chapters 1–4), the Handbook discusses why human rights must be protected and promoted if HIV is to be overcome, and what parliamentarians can do to provide leadership on HIV and to intensify their legislative, oversight and budgetary functions. Part II (Chapters 5–13) then provide concrete examples of legislation and other parliamentary action that advance evidence-informed and rights-based prevention and treatment, explaining in more detail the reasons why a particular type of legislation or other action is most effective and appropriate. Part III provides other useful background information on HIV for parliamentarians.

What parliamentarians can do: some key actions

The Handbook provides a very detailed discussion and analysis of why leadership is required on each of the issues listed below, as well as a list of actions that parliamentarians can take in their role as leaders. Only a few examples of key actions are highlighted here in this summary.

HIV testing and counselling

- **Raise awareness** of the potential benefits of HIV testing and counselling.
- **Publicly take an HIV test and disclose your status.**
- **Undertake legislative and policy reform** to ensure that scaling-up of HIV testing and counselling is linked to other HIV services and human rights protections.
- **Repeal policies and legislation requiring or authorizing mandatory or compulsory HIV testing.**

Eliminating stigma and discrimination

- **Prevent prejudice, discrimination and stigma.** Promote compassion and understanding within families and communities, in the workplace and across society. Speak out against stigma, discrimination, gender inequality and the other drivers of the epidemic, and demand that governments take action. Meet publicly with people living with HIV, and speak out for tolerance, non-discrimination and the rights of women, children and other vulnerable populations in the context of the epidemic.
- **Provide a visible example.** Parliamentarians, as entrusted political and social leaders, are role models that people look to emulate. By taking a clear stand on erasing stigma and wiping out discrimination, parliamentarians can make that special difference. For those parliamentarians who are HIV-positive, taking the courageous step of declaring their status would have a major impact on how members of the public subsequently perceive and treat people living with HIV.
- **Strengthen legislation, regulations and other measures to eliminate all forms of discrimination against people living with HIV and members of at-risk populations.**
- **Ensure that national AIDS authorities and their partners develop a prioritized, costed, and longer-term plan to fight stigma and discrimination.** Despite much rhetoric on stigma and discrimination, and despite the com-

mitments they expressed in the *Declaration of Commitment on HIV/AIDS* and the *Political Declaration*, few countries have developed longer-term, strategic plans or specific programmes to address stigma and discrimination. Instead, countries often implement small, one-off projects, without a clear understanding of how to sustain action over time, and without clear priorities or cost estimates. Parliamentarians can ensure that countries move from rhetoric to real, long-term action.

Prevention

- **Use every opportunity to speak out about the need to prevent the spread of HIV**, recognizing that governments have often shied away from undertaking comprehensive HIV prevention because of competing economic and political priorities and the association of HIV with issues such as sex, sex work, sex between men, and drug use. There is no doubt that these can be difficult and sensitive issues, but they must be addressed transparently, and informed by evidence, if an effective response to HIV is to be mounted.
- **Promote programmes that prioritize the HIV prevention needs of key affected groups and at-risk populations.** This is not only the right thing to do in terms of protecting the human rights of all members of society, it is also the best way to prevent HIV.
- **Reject coercive approaches to HIV prevention**, which are known to be ineffective. Such approaches include mandatory HIV testing, restriction of movement, and criminalization of harm reduction measures and HIV prevention modalities. These tend to drive individuals away from health information and services, have an adverse effect on prevention goals, and violate human rights. Effective HIV prevention measures are those that emphasize human dignity, responsibility and empowerment, through access to health information, services, and community support and participation.
- **Review and, if necessary, reform legal frameworks to ensure that people's ability to control their risk of infection through comprehensive programmes is protected.** In particular, this includes the following measures.
 - The elimination of gender-based inequalities that fuel the epidemic.
 - The removal of barriers to HIV prevention programmes, particularly laws or regulations that impede (a) the distribution of sexual health education and information; (b) the provision of condoms, sterile injecting equipment and other harm reduction measures; and (c) work with

members of vulnerable populations, including sex workers, men who have sex with men, people who use drugs, and prisoners, as well as groups demanding equal rights for women and advocating the rights of children.

- **Ensure that national authorities and their partners take stock of where, among whom, and why new HIV infections are occurring.** Understanding this enables countries to review, plan, adapt and prioritize their national responses to meet these needs.

Treatment, care and support

Parliamentarians in low- and middle-income countries can:

- ensure that countries **devote a greater proportion of national budgets to health** so that they can undertake and sustain broader health system strengthening;
- **reform national intellectual property legislation** to ensure that flexibilities in global trade rules (eg, TRIPS) are incorporated into national laws and regulations without delay to promote access to affordable generic HIV pharmaceuticals;
- **reform national patent laws in least developed countries** to allow national authorities the option of not providing any patent protection in the pharmaceutical sector until 2016, as provided in the *WTO Doha Declaration*;
- **encourage regional cooperation** to promote greater access to treatment;
- **take an active role in trade negotiations** to ensure that governments do not enter into regional and bilateral trade agreements that include intellectual property provisions with more extensive patent protection than required by the TRIPS Agreement.

Parliamentarians in high-income countries can:

- **advocate increased bilateral budget support to the health sector;**
- **discourage the use of recruitment policies that explicitly entice health workers from low- and middle-income countries** to high-income countries;
- **ensure that trade sanctions are not threatened or imposed by governments of low- and middle-income countries** that use the TRIPS flexibilities for greater access to affordable generic HIV medicines and other essential pharmaceuticals;

- oppose any provisions in bilateral, regional or multilateral treaties that create more extensive intellectual property protection than what has been agreed under global trade rules or that undermine the flexibilities in the TRIPS Agreement.

Reducing vulnerability among women

- **Secure legislative and policy changes to protect the rights of women.** Laws and policies that affirm and protect the rights of women are vital to the success of the AIDS response. Governments have repeatedly declared their commitment to improve the status of women and have acknowledged the linkage with HIV. In some areas, progress has been made. By and large, though, efforts have been small-scale, half-hearted and haphazard. For the response to the epidemic to be successful, national HIV responses need to be reoriented to support women's equality inside and outside the home, to protect women and girls from violence, and to change gender norms that put men and women at risk. Some countries have passed important legislation on issues such as domestic violence, equality in marriage, HIV-related discrimination, and property and inheritance rights. Yet strategies to enforce these laws and finance their implementation are rare. Parliaments and their members should lobby for the implementation of international agreements on gender equality and the protection of women's human rights, and for laws that uphold these. In particular, they can secure legislative and policy changes to:
 - protect women and girls from harmful traditional practices;
 - protect women and girls from violence;
 - protect women from marital rape;
 - ensure equality in domestic relations (including with regard to the property and inheritance rights of women and girls), and promote access to credit, skills training, education, and employment opportunities for women and girls.

Reducing vulnerability among children

- **Develop laws and policies that protect affected children.** Hardly anyone disputes children's right to HIV prevention, care and treatment. Nevertheless, in general, too little effort is being made to ensure that children receive the services they need. All actors, including parliaments and their members, must demonstrate leadership and act now to keep the next

generation free of infection. In particular, parliamentarians can take the following measures.

- Introduce or reform policies and legislation to define standards of protection and care for orphans and other vulnerable children, based on the best interests of each child. Fostering and adoption, birth registration, and provision of community-based care are among the key issues that need to be addressed.
- Advocate policies and laws to prevent discrimination against orphans and other vulnerable children, to protect the inheritance and property rights of orphans and widows, and to protect orphans and other vulnerable children from abuse, violence, exploitation and discrimination.
- Recognize that the rights of women are integrally linked to the rights of children, and secure legislative and policy changes to protect these rights.
- **Develop laws and policies that support prevention of mother-to-child transmission of HIV.**
 - Ensure that policies or laws require that all pregnant women are *offered* HIV testing and counselling, but are not tested mandatorily or without their informed consent.
 - Ensure that all pregnant women and adolescent girls living with HIV have access to the full range of methods for reducing the risk of transmitting HIV to their infants, including antiretroviral treatment, safer delivery practices and safer ways of feeding infants.
 - Ensure that programmes to prevent transmission from mother to child are properly linked with HIV services for HIV-positive mothers.

Reducing vulnerability among young people

- **Call for the provision of information about sexuality and sexual and reproductive health to young people before they become sexually active.** There is overwhelming evidence that the more educated young people are about sex, the more likely they are to delay having sex or to practise safer sex. Comprehensive sex education can reduce behaviours that put young people at risk of contracting HIV and STIs or that result in unplanned pregnancies.
- **Work to secure legislative and policy change to ensure:**
 - universal coverage with comprehensive and evidence-informed sexual and reproductive health education;

- that laws or policies do not restrict educational activities around HIV prevention in schools;
- removal of any legislative barriers to young people's access to HIV testing and counselling and to comprehensive HIV prevention measures.
- **Encourage programmes that help young people to stay in school.** Evidence has demonstrated that getting and keeping young people (particularly girls) in school dramatically lowers their vulnerability to HIV.

Reducing vulnerability among other populations at risk

Punitive approaches to drug use, sex work and homosexuality fuel stigma and hatred against people who use drugs, men who have sex with men, sex workers, and prisoners pushing them away from services aimed at preventing, treating, and mitigating the impact of, HIV. At the same time, the resources devoted to HIV prevention, treatment and care for these populations are not proportional to the HIV prevalence, which represents a serious mismanagement of resources and a failure to respect fundamental human rights. Both for public health and human rights reasons, leadership and action are sorely needed.

Men who have sex with men

- **Provide public support for prevention measures** for men who have sex with men, recognizing that, in all regions of the world, men who have sex with men are severely affected by HIV, but their needs have been largely ignored and under-funded. Many men who have sex with men also have sex with women. Neglecting their prevention needs can seriously affect the course of the HIV epidemic.
- **Remove policy and legal barriers to prevention and care.** In particular, repeal laws that criminalize same-sex acts between consenting adults in private, recognizing that vulnerability to HIV infection is dramatically increased where sex between men is stigmatized and criminalized. Enact anti-discrimination legislation to reduce human rights violations based on sexual orientation.

People who inject drugs

- Educate people about the fact that dependence on drugs is primarily a health issue and that over-reliance on criminal law approaches to drug use can lead to rapid spread of HIV – not only among people who use drugs, but also the general community.

- Remove legal barriers to prevention and care, such as laws and policies that prevent the provision of sterile injecting equipment or access to opioid substitution therapy. There is evidence that provision of sterile injecting equipment and opioid substitution therapy are feasible, effective as public health measures, cost-effective, and do not lead to increased drug use. The implementation of these measures is not only permissible under the international drug control treaties but is also consistent with – and arguably required by – States’ obligations under the international law of human rights.

Sex workers

- Speak out about the need to provide all sex workers with access to effective HIV prevention, treatment, care and support.
- Speak out against all forms of violence, exploitation and victimization directed against sex workers, and highlight the fact that sex workers have the same human rights as any other person.
- Acknowledge the fact that addressing the impact of criminalization and police abuse is a fundamental element of effective HIV programmes for sex workers.
- Review criminal legislation in the area of sex work (as well as other laws and policies, including municipal by-laws, that have an impact on sex work), with the aim of removing all barriers to HIV prevention, treatment, care and support for sex workers, as well as barriers to the respect for their human rights.

Prisoners

- Advocate the introduction of comprehensive prevention measures in prisons, and for the provision of health services that are equivalent to those in the community.
- Reform laws and policies to reform the prison system and reduce prison populations by, among other things, reducing pre-trial detention and developing alternatives to imprisonment.

A controversial issue: using criminal sanctions in cases of HIV transmission or exposure to HIV

- **Avoid rushing to legislate on this issue, in favour of careful consideration.** When considering the use of criminal sanctions, parliamentarians can use a number of guiding principles and need to take broader policy considerations into account. In particular, there is concern that cre-

ating HIV-specific criminal legislation will (a) further stigmatize persons living with HIV; (b) provide a disincentive to HIV testing; (c) create a false sense of security among people who are HIV-negative; and (d) impose an additional burden and risk of violence or discrimination upon woman, rather than assisting them by protecting them from HIV infection. Overall, the use of criminal law may be warranted in some limited circumstances. However, criminal law should not include specific offences against transmission of HIV but should, instead, apply general criminal offences to these circumstances. The criminal law may appropriately be applied to those who intentionally transmit HIV or recklessly expose others to a significant risk of infection, while not taking precautions or not disclosing their HIV status. However, criminal liability for negligent transmission or exposure should be avoided.

Purpose of the handbook

Summary

- The objective of this Handbook is **to assist parliaments and members of parliament in responding effectively to the HIV epidemic** by intensifying their legislative, budgetary, oversight and advocacy functions.
- It **builds upon the first edition of the Handbook**, which was published in 1999 by the Joint United Nations Programme on HIV/AIDS (UNAIDS) and the Inter-Parliamentary Union (IPU) and remains relevant.
- IPU resolutions have continued to call upon parliaments “to review and adjust legislation to ensure that it conforms to the *International Guidelines on HIV/AIDS and Human Rights*”. Therefore, the Handbook continues to emphasize the central legal and policy issues that governments have to address as they scale up access to prevention, treatment, care and support.
- It aims to **assist parliamentarians in becoming leaders, taking action, and making decisions on HIV-related law and policy reform that advance, and do not hinder, the effective response to AIDS.**

The objective of this Handbook is **to assist parliaments and members of parliament in effectively responding to the HIV epidemic** through intensifying their legislative, budgetary, oversight and advocacy functions; and to serve as a training tool for workshops on HIV for parliamentarians.

Parliamentarians need to be well-informed about all aspects of the HIV epidemic. They need to know how to ensure that they and their families do not become infected with HIV. They should know the updated HIV infection statistics in their own countries and regions. Most importantly, parliamentarians must be well-informed about the controversies and accepted international norms that surround HIV, as well as about the commitments national governments have made to scale up action against HIV and reach universal access to prevention, treatment, care and support.

This Handbook **builds upon the first edition of the Handbook**, which was published in 1999 by UNAIDS and IPU and remains relevant.¹ Nevertheless, at the first meeting of the IPU Advisory Group on HIV/AIDS in September 2006, members of the group decided that a second edition should be published. They felt that, because of the many significant developments since 1999 in the HIV epidemic and the response to it, the Handbook should be updated.

We believe that HIV/AIDS is one of the most serious threats facing the world at the beginning of the 21st century and it is vital that parliamentarians, in industrialised as well as developing countries, play our part in addressing the epidemic. In particular we have an important role in ensuring that laws and policies are respectful of human rights and promote public health.

– Statement by the members of the UK All-Party Parliamentary Group on AIDS (www.appg-aids.org.uk)

IPU resolutions – including the most recent HIV-related resolution adopted by the 112th Assembly in Manila in 2005 – have repeatedly called upon parliaments “to review and adjust legislation to ensure that it conforms to the *International Guidelines on HIV/AIDS and Human Rights*”. Therefore, the Handbook continues to devote particular attention to **assisting parliamentarians in taking action and making decisions on HIV-related law and policy reform**, by providing information on the critical role of human rights in the overall response to the epidemic. This has become even more important since governments – indeed, all United Nations Member States – have committed themselves (most recently in the 2006 *Political Declaration on HIV/AIDS*), to “overcoming legal, regulatory or other barriers that block access to effective HIV prevention, treatment, care and support, medicines, commodities and services”.²

Detailed and practical guidance on HIV-related law and policy reform is provided. The intention is to help legislators (the terms “legislator” and “parliamentarian” are used interchangeably herein) and other policy-makers develop laws that are consistent with public health and human rights principles. Diverse and innovative responses to the epidemic are encouraged when in accordance with international human rights norms.

The Handbook is primarily intended for use by members of parliament and their staff, whether they are in low-income, middle-income or high-income countries. While some of the examples described will not apply to all types of epidemics and all types of settings, parliamentarians everywhere should be familiar with them as they can – and should – become more involved in all aspects of the response to HIV, both at the national and international level.

Civil society organizations, networks of people living with HIV, national HIV programmes, and government institutions may also find the Handbook useful. The Handbook should be read together with the *International Guidelines on HIV/AIDS and Human Rights*.



Office of the United Nations High Commissioner for Human Rights (OHCHR) and the Joint United Nations Programme on HIV/AIDS (UNAIDS)

International Guidelines on HIV/AIDS and Human Rights
(2006 Consolidated Version)

INTRODUCTION

*Why parliamentary leadership
and action on AIDS are critical*

Summary

- AIDS is a global emergency, causing unparalleled human suffering, inflicting the single greatest reversal in human development, and spawning a secondary epidemic of human rights abuses.
- People in every region and every country are affected.
- Important progress has been made in recent years. In many countries, a strong foundation now exists on which to build an effective response to AIDS. Nevertheless, the situation remains grave and there are major weaknesses in the response in virtually all countries.
- The need for leadership and action is greater than ever. As local leaders close to communities, members of parliament have a particularly critical role to play.
- There are many barriers to greater involvement. Capacity-building, parliamentary collaboration and partnerships, and greater collaboration with civil society can help overcome these barriers.
- Many parliamentarians themselves are living with or affected by HIV.

AIDS is a global emergency

AIDS is widely acknowledged as a global health and development emergency and is one of the defining issues of our time. As measured by both its actual effect and its potential threat to the survival and well-being of people worldwide, AIDS is on par with challenges such as climate change and the threat of nuclear war.³ More than 25 million people have already died of AIDS, and the number of people living with HIV continues to increase. Every year, millions of people are newly infected with HIV. For every person infected with HIV or killed by AIDS, a family and a community lose, and so does their nation. In the countries most affected, the sickness and loss of productive adults have already worsened poverty, multiplied the risks of famine and impeded development. Education and health systems have come apart as deaths continue to occur among teachers and health professionals. Political stability and national security are threatened as the disease fells large numbers in government, the armed forces and the police, and the public at large.

In some way or another, we all live with HIV. We are all affected by it. We all need to take responsibility for the response.

– UN Secretary-General Ban Ki-moon at the General Assembly review of the Declaration of Commitment on HIV/AIDS, 21 May 2007

In July 2000, the UN Security Council declared AIDS a potential national and global security threat – the first and only disease so declared.⁴ In 2005, the *UNDP Human Development Report* concluded that “the AIDS pandemic has inflicted the single greatest reversal in human development”.⁵ In that year, AIDS caused a fifth of deaths globally among people aged 15–49 years. By 2010, an estimated 10 million people will need antiretroviral treatment (ART).⁶

A critical time to become more involved in the response

It is a critical time for parliaments and their members to become more engaged in the response to AIDS. Governments, through the 2005 World Summit Outcome, the Gleneagles Communiqué of the Group of Eight (G8) industrialized countries, and the *Political Declaration on HIV/AIDS*, promulgated at the UN General Assembly High Level Meeting in 2006, have established the **goal of getting as close as possible to universal access to HIV prevention, treatment, care and support by 2010**. These commitments build on the *Declaration of Commitment on HIV/AIDS*, adopted by governments at the 2001 United Nations General Assembly Special Session (UNGASS). These commitments and the goal of universal access form a solid framework of accountability. **In this environment, parliamentarians can play a critical role in helping to ensure that these targets are met** and, more generally, in overcoming the many challenges that remain in the overall response to AIDS.

- **Important progress has been made since the 2001 Special Session, but many countries have failed to fulfil the pledges specified in the *Declaration of Commitment*.**⁷ Some countries have made great strides in expanding access to treatment, but have made little progress in bringing HIV prevention programmes to scale. Other countries that are now experiencing a reduction in HIV prevalence are making only slow progress to ensure that treatment is available to those who need it.
- **In many countries, a strong foundation now exists on which to build an effective AIDS response, with increasing political commitment and partner coordination.**
 - Annual funding for the response to AIDS has increased substantially since the 2001 Special Session.
 - Domestic public expenditure by governments has significantly increased in some low- and middle-income countries.
 - Treatment access has expanded. Only an estimated 240 000 people in low- and middle-income countries received ART in 2001, but 1.3 million in 2005, and more than 2 million by the end of 2006.
 - In more than 70 countries surveyed, the number of people using HIV counselling and testing services quadrupled between 2001 and 2005.
 - Six of 11 African countries heavily affected by HIV reported a decline of 25% or more in HIV prevalence among 15–24-year-olds in capital cities.
 - Blood for use in transfusions is now routinely screened for HIV in most countries.

- **Nevertheless, the situation remains grave, with many challenges yet to be overcome.**
 - Financial resources continue to fall short of what is needed.
 - HIV prevention programmes fail to target those at greatest risk. As a result, HIV prevalence has grown among the most marginalized groups in society, such as sex workers, people who inject drugs, men who have sex with men, and prisoners.
 - Most people with HIV in low- and middle-income countries still lack access to ART – and often even to basic medical care.
 - In many parts of the world, coverage of other key interventions also remains unacceptably low. This includes, for example, interventions to: help people educate themselves about HIV; obtain access to HIV prevention commodities and services; protect people from discrimination and sexual violence; and empower them to participate in the response to, and live successfully in a world with, HIV.
 - Twenty-eight per cent of countries are still unable to screen all donated blood for one or more of the transfusion-transmissible infections, including HIV.

- **There are still significant weaknesses in the response to AIDS.**
 - The *Declaration of Commitment* called for 80% of pregnant women accessing antenatal care to have HIV prevention services available to them by 2005. However, by the end of 2005, only 9% of pregnant women had access to services that prevent HIV infections in infants.
 - Stigma and discrimination against people living with HIV, and against groups vulnerable to HIV and to human rights abuses, remain pervasive.
 - National governments, international partners and communities are failing to provide adequate care and support for the 15 million children orphaned by AIDS, and for millions of other children made vulnerable by the epidemic.

- **The response to AIDS is insufficiently grounded in the promotion, protection and fulfilment of human rights.**
 - In early 2006, participants at country and regional consultations on universal access to HIV prevention, treatment, care and support

overwhelmingly reported that legal, social and cultural barriers, including inequality between women and men, stigma and discrimination against people living with HIV, and discrimination against marginalized groups, are major barriers to access and are undermining the effectiveness of national responses to the epidemic.

- In the *Declaration of Commitment* and the *Political Declaration on HIV/AIDS*, governments fully recognized the importance of human rights and gender equality in national responses to HIV and committed themselves to action in these areas. But programmes promoting human rights in the HIV response have yet to be prioritized by national governments. This has to change if universal access is to become a reality, national responses are to be effective, and human rights are to be realized in the context of the epidemic.

- **The consistent leadership necessary to slow, stop and reverse the epidemic is not yet evident.**
 - The global response to AIDS stands at a crossroads. It must become substantially stronger, more strategic and better coordinated if countries are to achieve the agreed-upon target of getting as close as possible to universal access to HIV prevention, treatment, care and support. The countries most affected by HIV will fail to achieve Millennium Development Goals (MDGs) to reduce poverty, hunger and childhood mortality, and countries whose development is already flagging because of HIV will continue to weaken, potentially threatening social stability and national security, if the response does not increase significantly. As UNDP and others have concluded, even the future economic growth of highly populous countries with relatively low HIV prevalence at present, such as India,⁸ may be threatened in the absence of an effective response to AIDS.
 - The global response to AIDS must be transformed from an episodic, crisis-management approach to a strategic response that recognizes the need for long-term commitment and capacity-building, using strategies based on scientific evidence that address the immediate needs of those affected as well as the structural drivers of the epidemic.

BOX 1**Why HIV is an exceptional epidemic, requiring exceptional leadership and action by parliamentarians⁹**

HIV poses an exceptional threat to global progress and stability. In the last 25 years, the epidemic has grown from a few isolated cases to over 55 million infections, and the number of new infections continues to grow each year. Yet access to HIV prevention information and technologies remains sorely lacking. Nearly 25 million women, men and children have died, and only a fraction of the roughly 33 million people living with HIV are even aware of their infection. Fewer still have access to the HIV medicines they need to stay alive.

People in every region and every country are affected. Sub-Saharan Africa continues to bear the brunt of the global epidemic. But every region and every country is affected. One in every 50 adults is infected in the Caribbean. In Asia, rates of infection are highest in Cambodia, Myanmar and Thailand, but millions are infected in populous China and India. Infection rates in Eastern Europe and Central Asia are increasing rapidly, especially among sex workers and their clients, and people who inject drugs. While high-income countries have prevented full-scale epidemics, prevention efforts are stalling in many countries, and infection rates in poor and disadvantaged communities, including ethnic and sexual minorities, are increasing.

HIV has spawned a secondary epidemic of human rights abuses. Based on their actual or perceived HIV status, people have been thrown out of their jobs and homes, denied medical care, imprisoned and even killed. Abuses of every kind continue in most countries, presenting a huge barrier to defeating HIV. Even brutal atrocities committed against people living with HIV continue to be reported to, and corroborated by, associations of people living with HIV, UNDP, UNAIDS and civil society partners.

Lack of human rights protection, poverty and marginalization allow HIV to take root in society's most vulnerable populations. For example, there is often poor provision of services for men who have sex with men, sex workers and people who inject drugs, as a result of discrimination and political and social taboos. Young people and women are particularly vulnerable to infection due to their lack of economic and social power and autonomy in their sexual lives. They are often denied the tools and information required to avoid infection and cope with AIDS.

HIV poses unique challenges for health and social systems. Moving towards universal access requires systems that can sustain services to prevent HIV and treat AIDS on an everyday basis. Wherever possible, services should be integrated into comprehensive programmes, including those addressing tuberculosis (TB), malaria, other infectious diseases, and sexual and reproductive health. In many low-income countries, public health, education and other social service systems are already buckling under the weight of sickness and death from AIDS, and skilled workers are leaving for better opportunities elsewhere.

HIV is a social and cultural issue. Confronting the epidemic requires discussion and action on issues that some societies find uncomfortable – such as gender equality, sexual and reproductive health, sex work, homosexuality and injecting drug use.

HIV is a health issue. Confronting the epidemic requires a stronger integrated response to HIV, TB and other diseases, stronger primary health care, stronger maternal health care, stronger sexual and reproductive health programmes, and stronger paediatric care.

HIV is a development issue. The spread of HIV is both a cause and a consequence of poverty. Confronting the epidemic requires stronger action on education, nutrition and child survival.

HIV is a human security issue. In countries where nearly half of the adult population is living with HIV, the political, economic and social security of the country is threatened.

If left on its current course, HIV will prevent achievement of the MDGs in highly affected countries and will place more and more countries at risk of social and political instability.

What parliamentarians can do: an overview

Parliamentarians have a crucial role to play in helping achieve this transformation and are well-positioned to make a unique contribution to a comprehensive and rights-based national and international response to AIDS.

- As representatives of the people, you can reflect the voices and concerns of *all people*, including people living with or affected by HIV, members of marginalized communities, youth, women, consumers and providers of health services.
- As opinion-leaders and decision-makers, you can promote respect among your constituents for people living with HIV and encourage informed debate on issues related to HIV. You can help the public understand that even though HIV provokes prejudices and misconceptions because of its relationship to blood, sex, drug use, sickness and other often sensitive subjects, HIV can be effectively prevented and treated, like other diseases, if these prejudices and misconceptions are overcome.
- As lawmakers, you can design and adopt legislation that protects human rights, and advances (rather than hinders) effective prevention, care and treatment programmes, and you can oversee their implementation. Examples include laws prohibiting discrimination against people living with HIV and marginalized groups, prohibiting violence against women and protecting women's inheritance rights, ensuring HIV treatment for all in need, permitting the government to use trade flexibilities for access to generic medicines, and removing any legislative barriers to prevention technologies such as condoms, drug substitution therapies and sterile injecting equipment.

People's representatives have the potential to shape public opinion and can provide the leadership necessary to halt the spread of HIV and to meet the needs of those living with or vulnerable to HIV.

– J.D. Seelam, Member of Parliament (India), and Member of the IPU Advisory Committee on HIV/AIDS

- As overseers of government activity, you can ensure that government commitments on HIV are respected.
- As overseers of national budget appropriations, you can ensure that adequate and cost-effective funding is provided both to national AIDS programmes and to efforts to respond to HIV internationally, and that funding is steered to interventions that are informed by the best available evidence of effectiveness and based on fundamental human rights principles.

BOX 2

What parliamentarians in high-income countries can do

Promote interaction with parliamentarians in most-affected countries to fight the pandemic.

See the response to AIDS in its total context – as a human rights issue, a development issue, a fair-trade issue, a market-access issue, not simply a health issue.

Be aware of the impact of domestic decisions on health systems in low- and middle-income countries (e.g. recruitment of skilled health personnel in low-income countries for employment in health-care systems in high-income countries).

Do more to protect human rights and reduce poverty in most-affected countries – for example, through advocating market access, helping build infrastructure and increasing human and physical capacity in the health sector.

Promote the development of HIV vaccines and women-controlled prevention methods such as microbicides.

[Adapted from a list developed by Dr Elioda Tumwesigye, MP, Uganda, Chair of HIV/AIDS Committee]

What are some of the barriers to greater involvement, and how can they be overcome?

Some parliaments have been among the greatest champions of action against AIDS. In other countries, however, the level of involvement of legislatures and individual parliamentarians remains weaker, with insufficient parliamentary participation and oversight in policy-making and programmes. Reasons why parliamentarians are not more involved in HIV issues include the following.¹⁰

- **Strategic visions versus political endurance.** Most elected representatives operate on short-term agendas tied to their four- or five-year election cycle. The need to win the next election may conflict with the demand to serve posterity, including by addressing the long-term challenges of AIDS.

- **Stigma attached to HIV.** The severe stigma attached to HIV makes it a sensitive and sometimes politically unattractive issue to champion. A growing number of parliamentary initiatives are beginning to address the needs of orphans and other children made vulnerable by AIDS. But parliamentary leadership and action for other vulnerable populations, such as people who use drugs, men who have sex with men, sex workers, or prisoners, remain rare. Despite the fact that many parliamentarians are living with HIV, particularly in countries with generalized HIV epidemics, they have not disclosed their HIV status to the public, possibly fearing their positive HIV status would be used against them politically.
- **Weak oversight capacity.** Many executive branches have not developed a relationship of accountability with their parliaments in matters relating to HIV. Conversely, parliamentarians have considered the problem inherently as a health issue requiring intervention primarily by the executive.
- **HIV committees in parliaments.** It has been recommended that parliaments, particularly in countries with generalized HIV epidemics, but also in other countries, should form HIV-specific parliamentary committees. Yet very few have done so. In addition, membership in portfolio parliamentary committees is determined by the political party leadership, which rarely considers the commitment of the member to HIV-related issues.
- **Lack of institutional response.** Few studies have been carried out to investigate the impact of AIDS on parliaments. Workplace programmes for parliamentarians are scarce and rather weak.

Some of the ways in which these barriers could be overcome include the following.

- **Knowledge and capacity-building.** Parliamentarians have identified a need for training on the complexities of HIV and its policy implications, which go well beyond developing stronger health programmes. They should be provided with adequate resources and information and should allocate time to engage in HIV-related advocacy work in their constituencies. Such work could include workshops, seminars and visiting people affected by, and infected with, HIV. Capacity-building is also needed so that members of parliament can effectively oversee HIV-related matters.
- **Parliamentary collaboration and partnerships.** Parliamentarians can collaborate with similar national, regional and international coalitions of parliamentarians engaged in the response to AIDS. Examples of such initiatives are provided throughout this Handbook.

□ **Collaboration with civil society.**

Parliamentarians can develop and strengthen innovative partnerships with civil society within the country and abroad. In particular, they can work with AIDS service organizations and with associations of people living with HIV. One of the most valuable lessons learned in the last 25 years of the response to the epidemic has been that people living with HIV are not ‘victims’ or passive recipients of assistance; they are participants in their own destiny; they have rights and are capable of appropriately asserting and claiming them; they represent a major resource in designing, establishing and implementing prevention, care, treatment and ‘know your rights’ programmes; and they must be engaged if responses to HIV are to be effective. It is thus crucial that members of parliament consult people living with HIV, support them in mobilizing resources and claiming their rights, and actively involve them in HIV-related initiatives.

HIV-positive people, youth, women, marginalised people and civil society in general need parliaments to engage fully in the HIV response. We ask parliamentarians to show leadership in achieving universal access to prevention, treatment, care and support and in breaking stigma and discrimination. Collaboration with civil society is crucial in holding governments to account on their promises and commitments on HIV and AIDS.

– Marcel van Soest, Executive Director, World AIDS Campaign, 2007

BOX 3

An initiative to support parliamentarians in their response to AIDS

The Coalition of African Parliamentarians Against HIV and AIDS (CAPAH) is a pan-African network of likeminded parliamentarians committed to increasing their role in the response to the AIDS pandemic. Members of CAPAH want to improve the advocacy, policy-making and oversight role of parliamentarians in order to increase parliamentary participation in the response to AIDS. This network provides an opportunity for members from across the continent to share lessons learned and develop a community of practice dedicated to strong leadership in the response. It has asked the Parliamentary Centre to act as its secretariat.

For more information, see www.parlcent.ca/africa/CAPAH/index_e.php

Many parliamentarians are living with or affected by HIV

Finally, it is important to note that, in many countries, **parliamentarians themselves, along with parliamentary staff, are living with or affected by HIV.**

In a number of countries, there has been a sharp rise in the number of elected leaders who have died prematurely of illness, and the main reason for by-elections has changed from resignation and retirement, to death of relatively young politicians.¹¹ In Malawi, an official statement in 2000 by the then Speaker of the National Assembly disclosed that 28 members of parliament had died of AIDS-related diseases.¹²

In Zambia, 46 by-elections were held in the 20-year period between independence and the first reported AIDS cases (1964 and 1984). Of these, 14 were as a result of death and 32 as a result of resignations and expulsion. In the period between 1985 and 2003, 102 by-elections took place – 39 as a result of deaths, which is almost three times as many as in the previous and longer period. The cause of death is not recorded but 27 of the 39 people were in the vulnerable age range for AIDS-related deaths. Zambia's former Deputy Minister of Health has also declared publicly that political parties have lost people to AIDS.¹³

In addition, members of parliaments in many countries face the reality of AIDS in their respective constituencies by dealing with sickness, funerals, orphanhood and widowhood on a daily basis.

BOX 4**Global summary of the AIDS epidemic (December 2007)****Number of people living with HIV in 2007**

Total	33.2 million (30.6–36.1 million)
Adults	30.8 million (28.2–33.6 million)
Women	15.4 million (13.9–16.6 million)
Children under 15 years	2.5 million (2.2–2.6 million)

People newly infected with HIV in 2007

Total	2.5 million (1.8–4.1 million)
Adults	2.1 million (1.4–3.6 million)
Children under 15 years	420 000 (350 000–540 000)

AIDS deaths in 2007

Total	2.1 million (1.9–2.4 million)
Adults	1.7 million (1.6–2.1 million)
Children under 15 years	330 000 (310 000–380 000)

The ranges around the estimates in this box define the boundaries within which the actual numbers lie, based on the best available information.

For more information about HIV prevalence in countries around the world, see:

- (1) **WHO, UNICEF, UNAIDS. *Epidemiological Fact Sheets on HIV/AIDS and Sexually Transmitted Infections.* These fact sheets are regularly updated. For each country, a fact sheet with country-specific data can be retrieved via <http://www.who.int/hiv/en/>**
- (2) **UNAIDS. *Report on the global AIDS epidemic.* Every two years, UNAIDS releases an updated report on the global AIDS epidemic. Available via www.unaids.org**
- (3) **UNDP. *Regional Reports on HIV/AIDS.* Available via <http://www.undp.org/hiv/>**

PART I

The role of parliaments and their members in the response to AIDS

CHAPTER 1

Providing strong leadership

Summary

- The importance of leadership in the response to AIDS is widely recognized.
- Parliamentarians have a crucial role to play in influencing public opinion about AIDS, increasing public knowledge, and mobilizing involvement of society.
- They can promote openness and disclosure by testing for HIV and disclosing their HIV status, particularly if HIV-positive.
- Parliaments and parliamentarians looking to expand leadership and action on HIV should take the opportunity to review their own parliamentary policies and procedures to ensure they protect and promote the HIV-related human rights of staff.

The importance of leadership in the response to AIDS

AIDS represents the greatest leadership challenge of our time. Leaders everywhere, including members of parliament, need to demonstrate that speaking out about AIDS is a point of pride, not a source of shame. But leadership also means abandoning rhetoric, taking action and taking responsibility for initiating and promoting the rights-based response to the AIDS epidemic needed to achieve universal access to prevention, treatment, care and support for all.¹⁴

What parliamentarians can do: leadership, advocacy and representation¹⁵

- **Break the silence.** Use the facts to convince yourselves, your families, your colleagues and the public that HIV is a real and present danger; show how AIDS is affecting families, communities and the country – and how it has overwhelmed many countries.
- **Educate and inform, eliminating ignorance and fear.** Let your constituents, your peers and the public know clearly how one can and cannot contract HIV and what social and cultural factors may put some people more at risk of infection. Make it known that people living with HIV can live many productive years, particularly if they receive medical treatment (including antiretroviral therapy – ART), care and compassion, and if their rights are promoted, protected and fulfilled. Let people know to whom they can turn for treatment, care, support and additional information.

Parliaments should support events such as World AIDS Day. [Parliamentarians should undertake activities such as] leading rallies and adopting slogans engaging the media and other stakeholders in the fight against HIV/AIDS; openly demonstrating acceptance of [and] solidarity with people living with HIV/AIDS [and] the affected children and families; speaking out about HIV/AIDS using all opportunities and wearing the red ribbon at all public functions.

– Hon. Ledian Mafuru Mng'ong'o,
Founder/Chairperson, Tanzania Parliamentarians
AIDS Coalition, and Chair, CAPAH

- **Prevent prejudice, discrimination and stigma.** Promote compassion and understanding within families and communities, in the workplace and across society. You are in a unique position to speak out against stigma, discrimination, gender inequality and the other drivers of the epidemic, and demand that governments take action. Meet publicly and regularly with people living with HIV, and speak out for tolerance, non-discrimination and the rights of women, children, and other vulnerable populations in the context of the epidemic. Encourage sports stars and celebrities to engage in campaigns for the human rights of people living with, or vulnerable to, HIV. Support the roll-out of public information campaigns on tolerance, compassion, non-discrimination and gender equality. Support events such as World AIDS Day.

➔ *For information about World AIDS Day resources, themes, events and materials, see www.worldaidscampaign.info*

- **Give top priority to protecting the people most vulnerable to HIV and people living with HIV.** Advocate policies that prevent discrimination, intolerance and human rights violations. Fight to secure the full human rights of people living with HIV and others who are stigmatized. Include people living with HIV as equal partners in all your work on the epidemic. Give special attention to tackling both the root causes and the immediate problems that make sex workers, men having sex with men, and people who inject drugs most vulnerable to HIV. Pay special attention to prisons and other places of detention where there is a great risk of HIV being transmitted. Ensure that the human rights of other people vulnerable to HIV, such as migrant workers and refugees and internally displaced people, are protected. Speak out on controversial issues, not just those issues that will attract widespread public sympathy.

- **Provide a visible example.**

Parliamentarians are role models that people look to emulate. By taking a clear stand on erasing stigma and wiping out discrimination, you can make that special difference. For those parliamentarians who are HIV-positive, taking that courageous step forward to declare their status would make a significant impact on how society subsequently behaves and treats people living with HIV. When well-known figures come forward, it helps make HIV a non-controversial condition.

Let us give publicity to HIV/AIDS and not hide it.

– Nelson Mandela, former South African President, speaking in 2005 at the funeral of his son who died of AIDS.

BOX 5**An example of leadership and action:
Malawian Parliamentarians promote openness and disclosure**

In Malawi, the parliamentary speaker Sam Mpasu revealed that, between 1996 and 2000, 28 members of parliament had died from AIDS. In 2002, cabinet minister Thengo Maloya indicated that he had personally lost three children to AIDS and that 100 important officials had died from AIDS in the previous six years. In 2004, then President Bakili Muluzi revealed that his brother had died of AIDS and urged Malawians to challenge stigma and discrimination. Since then, he has repeatedly urged Malawians to be open about HIV and to go for voluntary counselling and testing. Like his predecessor, current Malawi President Dr Bingu wa Mutharika also tested for HIV and declared his HIV-negative status. Women parliamentarians have also openly been tested for HIV and encouraged others to do so.

- **Mobilize resources.** Influence government, social, religious and traditional leaders and public officials to take positive action and to hold themselves accountable. Establish parliamentary and public forums for debate about issues related to HIV. Use your constituency offices and political party meetings, and debate issues with communities to develop consensus on national policies.
- **Create a parliamentary focal point for HIV.** Help establish a parliamentary committee or strengthen an existing body to take on these responsibilities. Elect or appoint a key person to champion the cause of responding to HIV. As part of a comprehensive national strategy, detail the responsibilities of key ministries, such as the ministries of finance, health, education, labour and justice.
- **Advocate effective AIDS education.** Education is important for members of parliament, religious and social leaders and communities, and vital for school-age children and young people before they become sexually active. Young people have the right to the knowledge and skills that will enable them to make informed, responsible choices and to save their lives, including using preventive methods such as condoms. Every effort should thus be made to integrate education on AIDS within the national school curriculum and as part of other out-of-school activities proposed to children and adolescents. Helping parents and training health and social workers, educators and teachers to talk about particularly sensitive issues, including sex education, peer pressure, drug use, sexual orientation, stigma and discrimination or gender relationships, is also critical to promoting safe behaviours among young people and vulnerable populations.

- **Push for strong health and social services.** Health and social services need to provide universal, non-discriminatory access to voluntary, confidential counselling and testing; control of sexually transmitted infections; youth-friendly and gender-sensitive sexual, reproductive health and family planning programmes, including condoms; safe blood-transfusion services; drug and alcohol rehabilitation; and sterile needle and syringe programmes for people who inject drugs. Every effort needs to be made to expand access to ART for all who need it. Social services should help strengthen community- and home-based support for people living with HIV, their families and caregivers. They should also provide child-protection services and shelters for women, sex workers and children living on the street.
- **Fight poverty and deprivation.** HIV and related conditions, such as TB, thrive on economic hardship, inequality and deprivation. The spread of HIV makes even more pressing the need for broad-based human development. More than ever, parliamentarians need to forge national, regional and international partnerships that address the constraints to development, whether due to gender inequality, budgetary shortfalls or adverse terms of trade or international debt.
- **Advocate better policies, laws and practices.** Finally, advocate better policies, laws and practices that facilitate, rather than hinder, effective prevention, care, treatment and support. **These are described in detail in Part II of the Handbook.**

Leadership by example: reviewing parliamentary policies and procedures

Parliaments and parliamentarians looking to initiate or expand work on HIV should take the opportunity to review their own policies and procedures to ensure that they protect and promote the HIV-related human rights of all staff employed by parliament and parliamentarians. Asking the following questions will facilitate this process.¹⁶

- Are there workplace policies prohibiting HIV-related discrimination?
- Is it clear in recruitment procedures that applications are encouraged from people living with HIV?
- Is voluntary and confidential HIV counselling and testing easily accessible to staff?
- Do health benefits include coverage for HIV-related treatment?
- Is reasonable accommodation (e.g. flexible or reduced working hours) available to persons with disabilities, or people living with conditions that are periodically disabling (including HIV)?

Reviews of internal policies should engage staff from all levels, fostering commitment to protecting and promoting HIV-related human rights, including in the workplace, and promoting staff knowledge on HIV-related issues. New staff induction and internal training programmes should include a component on HIV and human rights. Local groups of people living with HIV, and AIDS service organizations, can be good sources of information or possible trainers and educators.

Efforts should also be made to achieve gender balance and to include representatives of marginalized groups as employees.

BOX 6

An example of leadership and action: Pacific Parliamentarians become champions in leading the response to AIDS

The Pacific Parliamentary Assembly on Population and Development (PPAPD) hosted a Regional Meeting in Suva, Fiji in October 2004 on "The Role of Parliamentarians in the Fight Against HIV/AIDS in the Pacific Region". The meeting was attended by more than 70 Pacific Parliamentarians and 70 AIDS advocates, and encouraged parliamentarians to become "champions and icons" in leading the response to AIDS in Pacific communities. The meeting's objectives were to:

1. inform parliamentarians about HIV and brief them on the trends of HIV in the Pacific region;
2. discuss the impact of the AIDS epidemic as a wider development issue and in the context of the Millennium Development Goals;
3. solicit political support and commitment from Pacific Parliamentarians and national leaders in the response to AIDS;
4. discuss practical ways to translate political commitments into action;
5. foster opportunities for Pacific Parliamentarians and people living with HIV to jointly advocate prevention, treatment and support programmes.

The meeting culminated in the signing of the Suva Declaration on HIV/AIDS by Pacific Parliamentarians, documenting their support and commitments for taking action in the response to AIDS.

For additional information and a copy of the *Suva Declaration*:

http://pacific.unfpa.org/news/pr_MDG.htm

CHAPTER 2

Shaping supportive laws and policies

Summary

- The protection of human rights is essential to ensuring an effective response to AIDS.
- One of the most important roles for parliaments and their members is to ensure that legislation protects human rights, and advances (rather than hinders) effective HIV prevention, care and treatment programmes.
- Governments have committed themselves to intensifying efforts to overcome “legal, regulatory or other barriers that block access to effective HIV prevention, treatment, care and support, medicines, commodities and services”, as well as “efforts to enact, strengthen or enforce, as appropriate, legislation, regulations and other measures to eliminate all forms of discrimination against, and to ensure the full enjoyment of all human rights and fundamental freedoms by, people living with HIV and members of vulnerable groups” (*Political Declaration on HIV/AIDS*, 2006). Parliamentarians have made similar commitments in a number of IPU resolutions.
- The *International Guidelines on HIV/AIDS and Human Rights* and this Handbook are important resources for governments seeking to fulfil these commitments. There are many ways in which parliamentarians can assist.

One of the most important roles for parliaments and their members is that of enacting new, or reforming existing, legislation to ensure that it protects human rights, and advances (rather than hinders) effective HIV prevention, treatment and care programmes. Whether it be constitutional amendments to prohibit discrimination against people living with HIV or against those most vulnerable to infection, legislation to ensure the rights of school-age children to be educated on how to protect themselves as they grow older, or amendments to national intellectual property legislation to ensure that the World Trade Organization (WTO) *Agreement on Trade-Related Aspects of Intellectual Property* (the TRIPS Agreement or TRIPS) flexibilities are incorporated into national laws, to name only a few areas of concern, legislators are critical to ensuring the effectiveness of responses to the epidemic.

To date, the parliamentary record on HIV legislation is mixed. While some parliaments have passed legislation that advances effective prevention, treatment and care programmes (see the examples highlighted in text boxes throughout this Handbook), other parliaments have seen bills on HIV or related issues (such as domestic relations, gender-based violence, and discrimination) languish for years on the parliamentary agenda. Alternatively, they have passed legislation that fails to protect human rights and advance evidence-informed prevention and treatment, instead authorizing coercive measures that have proven to be ineffective, such as mandatory or compulsory HIV testing of certain people or in certain situations. This chapter discusses why human rights must be protected and promoted if HIV is to be overcome. Chapters 5 to 12 then provide concrete examples of legislation

that advance evidence-informed and rights-based prevention and treatment, and explain in more detail the reasons why a particular type of legislation is most effective and appropriate.

Why human rights must be protected and promoted if HIV is to be overcome

Throughout the response to AIDS, the following facts have become clear.

- The **protection of human rights is essential** to safeguard human dignity in the context of HIV and to ensure an effective response. Where human rights are not protected, people are more vulnerable to HIV infection. Where the human rights of HIV-positive people are not protected, such individuals are at greater risk of stigma and discrimination, and may become ill, unable to support themselves and their families; if not provided treatment, they may die.
- **An effective response to AIDS requires the implementation of all human rights** – civil and political, economic, social and cultural – in accordance with existing international human rights standards. Importantly, this includes protecting fundamental rights at work, particularly with respect to discrimination and stigmatization in the workplace.
- **Public health interests do not conflict with human rights.** On the contrary, it has been recognized that, when human rights are protected, fewer people become infected and those living with HIV and their families can better cope with AIDS.
- **A rights-based, effective response to the HIV epidemic involves establishing appropriate government institutional responsibilities, implementing law reform and support services, and promoting a supportive environment** for groups vulnerable to HIV and for those living with HIV.
- In the context of HIV, international human rights norms and pragmatic public health goals require States to **adopt measures that may be considered controversial**, particularly regarding the status of women and children, sex workers, people who inject drugs and men who have sex with men. It is, however, the responsibility of all States to identify how they can fully meet their human rights obligations and protect public health within their specific contexts.

BOX 7**What do human rights have to do with HIV?¹⁷**

Human rights are inextricably linked with the spread and impact of HIV on individuals and communities around the world. A lack of respect for human rights fuels the spread, and exacerbates the impact, of the disease. At the same time, HIV undermines progress in the realization of human rights. This link is apparent in the disproportionate incidence and spread of HIV among key populations at higher risk, and particularly those living in poverty. It is also apparent in the fact that the overwhelming burden of the epidemic today is borne by low- and middle-income countries. AIDS and poverty are now mutually reinforcing negative forces in many of these countries. Human rights are relevant to the response to AIDS in at least three ways:

They decrease vulnerability to infection and to impact

Certain groups, including women, children and youth, sex workers, people who inject drugs, men who have sex with men, and prisoners, are more vulnerable to contracting HIV because they are unable to realize their civil, political, economic, social and cultural rights. For example, individuals who are denied the right to freedom of association and access to information may be precluded from discussing issues related to HIV, participating in AIDS service organizations and self-help groups, and taking other preventive measures to protect themselves from HIV. Women, and particularly young women, are more vulnerable to infection if they lack access to information, education and services necessary to ensure sexual and reproductive health and prevention of infection. The unequal status of women also means that their capacity to negotiate in the context of sexual activity is severely undermined. People living in poverty often are unable to access HIV care and treatment, including antiretrovirals.

They decrease discrimination and stigma associated with HIV

The rights of people living with HIV often are violated because of their presumed or known HIV-positive status, causing them to suffer both the burden of the disease and the consequential loss of other rights. Stigmatization and discrimination may obstruct their access to treatment and may affect their employment, housing and other rights. This, in turn, contributes to the vulnerability of others to infection, since HIV-related stigma and discrimination discourage individuals infected with, and affected by, HIV from contacting health and social services. The result is that those most needing information, education and counselling will not benefit even where such services are available.

They make national responses more effective

Strategies to combat the HIV epidemic are hampered where human rights are not respected. For example, discrimination against, and stigmatization of, vulnerable groups such as people who inject drugs, sex workers, and men who have sex with men drives these communities underground. This inhibits the ability of social service organizations to reach these populations with prevention efforts, thereby increasing these groups' vulnerability to HIV.

The International Guidelines on HIV/AIDS and Human Rights: an essential resource

The International Guidelines on HIV/AIDS and Human Rights, issued in 1998 at the request of the United Nations Commission on Human Rights (now the Human Rights Council) and reissued in 2006, are an essential resource for governments seeking to fulfil the commitments they made to overcome legal barriers to an effective HIV response. The Guidelines consist of 12 guidance points, each describing appropriate legislative and policy responses that are required for an effective public health response to the epidemic.

➔ *The text and commentary of the Guidelines are available via www.unaids.org or www.ohchr.org/english/issues/hiv/guidelines.htm.*

➔ *For an easy-to-read summary of the Guidelines, see: [International Council of AIDS Service Organizations. *Advocates Guide to the International Guidelines on HIV/AIDS and Human Rights*. Toronto: ICASO, 1999. Available via \[www.icaso.org\]\(http://www.icaso.org\).](#)*

The Commission on Human Rights asked States to take all necessary steps to ensure the respect, protection and fulfilment of HIV-related human rights outlined in the Guidelines, and urged States to ensure that their laws, policies and practices comply with the Guidelines.¹⁸ The UN Secretary-General has submitted reports to the Commission, and to its successor, the Human Rights Council, on steps taken by governments and the United Nations (UN) to promote and implement the Guidelines.¹⁹

As the epidemic has evolved, the lessons learned from it confirm that the protection of human rights in the context of HIV reduces suffering, saves lives, protects the public health, and provides for an effective response to HIV.

– Louise Arbour, UN High Commissioner for Human Rights, 2006

IPU resolutions – including the most recent resolution focusing on AIDS adopted by its Assembly in Manila in 2005 – also have called upon parliaments “to review and adjust legislation to ensure that it conforms to the *International Guidelines on HIV/AIDS and Human Rights*”.

In their foreword to the 2006 consolidated version of the Guidelines, Louise Arbour, United Nations High Commissioner for Human Rights, and Peter Piot, Executive Director, UNAIDS, urge governments “to benefit from and build upon the Guidelines”, and to “continue to find ways to operationalise their commitment to protect human rights in the response to HIV”.

What parliamentarians can do to establish supportive legal frameworks

Holding governments to their promises

Both at the 2001 UNGASS on HIV/AIDS and at the 2006 High Level Meeting, governments recognized the centrality of human rights and a rights-based approach in national responses to HIV. The *Declaration of Commitment on HIV/AIDS* (2001) and the *Political Declaration on HIV/AIDS* (2006) express both governments' realization that human rights must be protected if AIDS is to be overcome and governments' commitments to achieve concrete, time-bound targets. The Preamble of the *Declaration of Commitment* acknowledges that:

The full realization of human rights and fundamental freedoms for all is an essential element in a global response to the HIV/AIDS pandemic, including in the areas of prevention, care, support and treatment, and that it reduces vulnerability to HIV/AIDS and prevents stigma and related discrimination against people living with or at risk of HIV/AIDS; without human rights, many of even the best improvements in programs and policies will fail (paragraph 16).

In his 2006 report on progress made in the implementation of the *Declaration of Commitment*, the UN Secretary-General highlighted the fact that many countries had not met their commitments and that:

legal, social and cultural barriers are undermining access to interventions for those most at risk of HIV infection and most affected by AIDS. Violence against women, drug users, sex workers and men who have sex with men and other HIV-related human rights abuses are still widespread.²⁰

The Secretary-General noted that “HIV-related human rights are not high enough among the priorities of national governments, donors or human rights organizations” and that “the development and enforcement of supportive laws and protection of human rights – including the rights of women and children – must remain priorities”.²¹

Parliamentarians have an important role to play here and should demand that governments live up to their promises and move from rhetoric to action on HIV-related human rights.

Following up on IPU resolutions and enacting supportive legislation

Not only national governments, but also members of parliament have made commitments to adopt a rights-based approach to HIV and to move swiftly to reform legislation to ensure that it advances effective HIV prevention, treatment, care and support. In particular, in a number of resolutions, the

Assembly of the Inter-Parliamentary Union called upon parliaments and governments to ensure that their laws, policies and practices respect human rights in the context of HIV.²² However, in practice, in many countries, legislation continues to hinder, rather than advance, effective action against AIDS. Reviewing existing legislation and reforming it to ensure that it protects human rights and enables effective and evidence-informed action should therefore be a crucial role of parliaments and their members.

➔ *For more details about what parliamentarians can do to establish supportive laws and policies, and examples of such laws and policies, see Part II of the Handbook.*

BOX 8

An example of leadership and action: Member of parliament involves nongovernmental organization in development of Indian HIV/AIDS Bill

The Lawyers Collective HIV/AIDS Unit was requested by Shri Kapil Sibal, Member of Parliament, and the Indian National AIDS Control Organisation (NACO) to prepare a draft law on HIV/AIDS to be presented to the Parliament in April 2003. This initiative received commitment from the Indian Government. The Lawyers Collective undertook a comprehensive examination of legal developments around HIV in other countries in order to contextualize the Indian experience within the global pandemic and borrow from other legislative experiences to inform the draft legislation for India. The Lawyers Collective then conducted nationwide consultations on the draft legislation by involving and learning from representatives of the various sectors that are affected by the epidemic. The consultation feedback was then incorporated, where appropriate, in the draft legislation. At the time of writing, the version of the draft law was pending with the Government of India, and was likely to be tabled in Parliament later in 2007.

For additional information: www.lawyerscollective.org/%5Ehiv/Draft_Law_On_HIV.asp

BOX 9

An example of leadership and action: Parliamentarians consider legislative measures to combat the spread of HIV in Central Asia

The Parliament of Kyrgyzstan convened an international parliamentary conference entitled "The HIV Epidemic in Central Asia and Eastern Europe: Legislative Measures to Combat the Spread of HIV and Priorities for Regional Cooperation" in Bishkek in September 2006. Participants agreed to form a Central Asian parliamentary working group on HIV issues with the goal of improving the legislative framework supporting the fight against the spread of HIV in Central Asia.

For additional information about this initiative: <http://web.worldbank.org>

Assisting with implementation of the *International Guidelines on HIV/AIDS and Human Rights*

Legislators and government policy-makers, because of their ultimate responsibility for designing and implementing policies on HIV, are the principal audience for which the Guidelines were drawn up.

Parliamentarians can assist with implementation of the Guidelines by:

- educating their peers about the Guidelines at national, provincial and local levels to encourage promulgation, acceptance and endorsement;
- devising a strategy for disseminating the Guidelines and this Handbook to key actors and developing action plans for monitoring and implementation of priority issues;
- holding a parliamentary inquiry to look at the government's policies relating to the Guidelines (see Box 10 for an example of such an activity);
- participating in consultative review and reform of the law, by drafting either government-sponsored or private members' bills.

BOX 10

An example of leadership and action: Parliamentarians hold enquiry about government's compliance with the *International Guidelines on HIV/AIDS and Human Rights*

In 2001, the United Kingdom All-Party Parliamentary Group (AAPG) on AIDS held a Parliamentary Inquiry to look at the UK Government's policies relating to the *International Guidelines on HIV/AIDS and Human Rights*. The report of that inquiry highlighted "the major failures of the UK Government to address the impact of its laws and policies on those infected with, affected by and vulnerable to HIV and AIDS".²⁵ In 2006, the Group proposed to conduct a human rights audit of the current policies of the UK Government in relation to HIV, to examine how far its recommendations from 2001 have been put into practice. It asked for evidence from nongovernmental organizations (NGOs) and individuals on the following issues:

- HIV-related domestic practice and policies and how they comply with, or infringe upon, the UK's human rights obligations;
- the impact of the UK's stance (including derogations or reservations) on international human rights treaties;
- the impact of the Human Rights Act on HIV policy in the UK and the potential and limitations of the Act to challenge breaches of the human rights in the context of HIV.

The UK All-Party Parliamentary Group on AIDS was established in 1986 and aims to raise awareness of HIV in Parliament and to encourage balanced policies based on accurate information. It ensures that HIV is kept on the political agenda through debates and questions in the House of Commons and the House of Lords. It acts as a bridge between Parliament and the statutory and voluntary sectors, providing a forum for the exchange of information. It produces briefing papers on topical issues for parliamentarians and an Annual Review summarizes current activities and objectives.

Additional information about the work of the UK APPG can be found at

<http://www.appg-aids.org.uk/>

Ensuring that governments ratify and fulfil their obligations under human rights treaties and declarations

There is no international treaty or covenant that specifically addresses HIV. However, a number of provisions from international and regional human rights treaties and declarations have significant implications for the effectiveness of the response to AIDS. They are also vital tools for parliamentarians to use in enacting and reforming laws. **Parliamentarians should check whether their government has ratified the core treaties and the existing regional treaties and, if not, take action to ensure that it does.**²⁴

In addition, parliamentarians have a role to play in implementing other human rights measures, including treaty body ‘concluding observations’, recommendations made by the ‘special procedures’ and the ‘general comments’ generated by the treaty bodies.

➔ *For more details about the many provisions in human rights treaties and declarations that have implications for the response to AIDS, see Annex 2 in Part III of this Handbook.*

➔ *For fact sheets on treaty bodies and special procedures, as well as reports from the special rapporteur on the right to health, see:*
<http://www.ohchr.org/english/about/publications/docs/fs30.pdf>
<http://www.ohchr.org/english/about/publications/docs/factsheet27.pdf>
<http://www.ohchr.org/english/bodies/chr/special/index.htm>

Ensuring that national laws are properly implemented and enforced

Many countries have made efforts to reform HIV-related laws and ensure conformity with the international commitments made by governments. However, not all of these laws and policies reflect the commitments made. In addition, even where they are rights-based, evidence-informed, and supportive of best practice, programmes and practices have not always changed in accordance with the new laws.

- Despite the existence of laws protecting inheritance and property rights, many women continue to face the loss of their homes and property when their husband dies of AIDS. This can be due to lack of law enforcement, existence of contradictory customary law, unwillingness on the part of the judiciary to apply the law, reluctance to bring a complaint due to the public nature of legal proceedings, or lack of legal aid to help women bring legal claims forward.

- People living with HIV are often dismissed from their job when their status becomes known in the workplace, despite laws and regulations that should protect them.

For legal reform to have the greatest impact, it must be accompanied by “effective public education about non-discrimination and human rights in relation to HIV”²⁵ and the capacity of individuals to vindicate their rights.

It is essential that labour inspectors, magistrates and judges be sensitized to the issues and trained to ensure full implementation of laws relating to the prohibition and elimination of stigma and discrimination associated with HIV in the workplace.

Furthermore, even those individuals who know their legal rights often face barriers to enforcing them. These barriers can include issues of access in terms of availability, location and cost. In many countries, private legal counsel is unaffordable and the legal system is unavailable to the majority of the population.

Thus, parliamentarians should encourage and undertake assessments of how laws are being applied, and what barriers exist to fully implementing the law, and advocate actions that result in the better implementation and enforcement of laws where these are based on evidence and human rights principles.

CHAPTER 3

Increasing parliamentary oversight

Summary

- As part of their moral and legal authority to monitor government business, parliaments and their members can do many things to increase oversight of HIV-related issues. These include: strengthening the response to HIV within parliament (e.g. by establishing HIV standing committees and by taking a multisectoral approach to HIV, requiring more committees to integrate HIV into their work); increasing research support to members of parliament and parliamentary committees and creating effective partnerships with civil society organizations engaged in the response to HIV; increasing representation of women in parliament; and improving monitoring of AIDS spending and aid effectiveness.
- Governments have adopted several international agreements that include promises relating to HIV. A particularly important role of members of parliament is to hold their governments to these promises.

What parliaments and their members can do to increase oversight of HIV-related issues

Strengthen and expand the response to HIV within parliament

Currently the focus on HIV in parliaments is largely located at two levels: with individuals who have a personal commitment to addressing HIV issues; and with parliamentary committees that have a social welfare agenda, such as health, education and social development committees, or with a formal subcommittee for HIV.

In order to strengthen the response to HIV within parliament, every parliament should:

- strive to have an HIV standing committee and, wherever possible, convert existing subcommittees on HIV into full standing committees;
- facilitate the creation of interest groups or networks within national parliaments focused on HIV²⁶ (with membership including sitting members of parliament from any of the parliamentary committees, parliamentary staff and former members of parliament).

HIV/AIDS has become a serious socio-economic and developmental concern. We have no choice but to act, and act with firmness, with urgency and with utmost seriousness. To push this effort forward we constituted the National Council on AIDS and I myself head this Council so that the combined attention of the Government as a whole is given to our campaign against AIDS.

– Dr Manmohan Singh, Prime Minister of India

In addition, to further expand the response to HIV within parliament, a multisectoral approach is needed.

BOX 11

Examples of parliamentary committees and coalitions

In the **United Republic of Tanzania**, TAPAC, the Tanzanian Parliamentarians AIDS Coalition, was created by a group of 15 members of parliament in 2001. Membership increased quickly to nearly half of the members of parliament. TAPAC soon began fact-finding activities, disseminating information, and proactive investigation into the national HIV response, with the objective of mobilizing members of parliament and officials at the national and community levels to strengthen the national response.

In **Uganda**, a Parliamentary Standing Committee on HIV/AIDS was formed in August 2002. The Committee has carried out numerous activities, guided by a strategic plan drawn up with support from the Association of European Parliamentarians for Africa (AWEPA).

In **Brazil**, 50 parliamentarians from across the political divide formed the Parliamentary Front for Health. They work together to ensure that AIDS is kept high on the political agenda and to break down prejudice and stigma.

In **India**, an All-Party Parliamentarians' Forum on HIV/AIDS (PFA) was formed in March 2000 to engage in strengthening and supporting the response to the epidemic by reinforcing and sustaining leadership at national, provincial and regional levels. PFA's actions have included: reaching out to State Legislators and forming State Legislators' Forums on AIDS in several States; participating in the Colloquium on HIV/AIDS: The Law and Ethics; putting together a Study Group on the Role of Parliamentarians in Combating HIV; and organizing a face-to-face meeting with people living with HIV.

For more detailed information, see: <http://www.pfaindia.in>

Create effective partnerships with civil society

Many parliaments operate in an environment of limited resources, which can restrict the availability of internal research and administrative support to members and committees. Lack of technical support weakens members' capacities as they have fewer independent sources of information and become more dependent on the executive government as their main source of information.

Effective partnerships with extra-parliamentary institutions can help meet this challenge. These partnerships can include civil society organizations with research capacity and expertise as well as HIV service providers who are in a position to comment with authority on government programmes. This collaboration can achieve at least two objectives: (1) provide greater information and knowledge to these groups on government policies and programmes; and (2) provide feedback on government policies and programmes from these groups to members of parliament, thereby improving oversight of the response to HIV. The following actions can help establish partnerships with civil society for effective oversight of the AIDS response.²⁷

- Parliamentary committees can request civil society organizations to testify in budget hearings.
- Members of parliament can work with other organizations such as AIDS service organizations, groups of persons living with HIV, women's groups, groups representing key populations such as sex workers, men who have sex with men, people who use drugs, and prisoners, traditional leaders, trade unions, human rights commissions and faith-based organizations.
- Members of parliament can request that a non-partisan NGO assist with the coordination of a parliamentary network/association on HIV in order to ensure non-partisanship in its work.
- Members of parliament can identify relevant civil society organizations that can assist committees and individual members of parliament with analysing bills, motions and draft laws with an HIV lens in order to make relevant amendments.

Enhance public participation

Citizens with direct experience of HIV as well as government policy and programmes are perhaps the greatest resource for all members of parliament and parliaments. Engagement with people living with HIV and members of key populations improves representative democracy and oversight of the response to the epidemic.

Demand greater interaction between parliamentary committees and the executive political leadership

Leaders in government interact with parliamentary committees largely on an ad-hoc basis. Given the severe impact of HIV in many countries and the threat in others, more direct, structured, high-level accountability and oversight by parliaments could greatly improve the quality and scale of the AIDS response.

BOX 12

Key resources: Parliaments, politics and HIV

In spite of the importance of parliaments in ensuring good democratic practice, there is a lack of literature describing the role of parliaments in determining HIV-related priorities. This is particularly the case in relation to parliamentary oversight.

Research by the Institute for Democracy in South Africa (IDASA) and the Canadian Parliamentary Centre, focusing on the effective use of parliamentary oversight in the national responses to HIV, has filled some of the existing knowledge gap. The research is an assessment of how the national parliaments of Botswana, Ghana, Kenya, Mozambique and South Africa use their oversight function to inform and

monitor the national HIV responses. Other parliaments can use the findings and recommendations to improve the oversight function in their HIV responses. This chapter is based, in part, on the research's findings.

For more information, see: Governance and AIDS Programme, IDASA. *Parliaments, politics and HIV/AIDS*.

**The report and other related documents are available via www.idasa.org.za
or www.parlcent.ca/index_e.php.**

Increase and expand oversight in the budget process

Members of parliament and parliamentary committees can increase their role in the budget process in the following ways.²⁸

- Ensure that budget allocations are in line with approved government priorities for HIV.
- Ensure that budgets reflect additional priorities that emerge from constituency work.
- Investigate the total amount, within the health budget (and other budgets), earmarked for HIV programmes, as well as for health and social systems strengthening.
- Ensure that budget allocations are sufficient to meet international commitments (e.g. *Declaration of Commitment on HIV/AIDS* and the African Union Heads of State and Government commitment in the 2001 *Abuja Declaration*).
- Lobby for budgets to include a specific line item for HIV in the health budget and other budgets, which will assist members of parliament in monitoring spending on HIV.
- Monitor whether government agencies are spending allocations as per approved budgets and, if applicable, establish the reasons for under-spending funds for HIV.

BOX 13

Key resources: Budget-monitoring and resource-tracking for AIDS

The Centre for Economic Governance and AIDS in Africa (CEGAA) aims to contribute to improved economic governance, fiscal policy and financial management and accountability, with specific attention to improving the response to AIDS. It is a potentially very valuable resource for parliamentarians. While it focuses on Africa, its work is useful for parliamentarians and others interested in budget monitoring for HIV in all regions. Among the primary objectives of CEGAA is to build the capacity of, and provide support to, government representatives, civil society and parliamentary efforts to monitor the effectiveness of allocation and use of financial resources for HIV, and to advocate increased accountability, transparency and improved budgetary

processes and execution. In the long term, these efforts will enable CEGAA and country partners to:

- make recommendations to national governments, parliamentarians, international donors and financing institutions, as well as organizations working in the field of AIDS, to improve their economic governance, their absorptive capacity and efficiency of spending;
- support the efforts of donors in assessing each country's need for, and utilization of, development aid for the campaign against AIDS;
- hold governments accountable to their international and regional commitments in terms of the economic response to HIV, such as the MDGs, UNGASS and Abuja+5 goals (whereby, five years after they adopted the *Abuja Declaration and Framework for Action for the Fight against HIV/AIDS, TB and Other Related Infectious Diseases in Africa* (2001), African leaders made additional commitments to achieve universal access);
- develop and support groups or networks advocating more effective economic governance, accountability and transparency, both nationally and internationally.

For more information, see: www.cegaa.org. **The web site also contains useful links to other sites that assist with budget-monitoring efforts, such as the site of the International Budget Project:** www.internationalbudget.org

Increase representation of women in parliament

Increasing the representation of women in parliament is another important aspect of effective oversight and equitable representation.²⁹ To date, only a few countries have adequate representation. This “entrenches a largely patriarchal framework for parliamentary oversight of HIV/AIDS and silences the gender issues that should be central to this function...”³⁰

Improve monitoring of aid effectiveness³¹

When parliaments in low- and middle-income partner countries are informed of aid programmes, they can influence how that aid is put to use. More specifically, through the budget process, parliamentary committees can scrutinize whether aid spending is aligned with national priorities and suitably responds to the needs of all the country's people. Committees can also use public hearings and consultations to assess whether aid programmes are properly implemented, whether there is evidence of corruption or mismanagement of funds, and whether aid is reaching key populations.

Parliaments in donor countries also have a duty to hold their governments to account. Review of the budget estimates offers members of parliament the opportunity to find out whether a government is living up to its commitment to the aid target of 0.7% of gross national income.³² They can also investigate whether official development assistance (ODA) is targeting countries most in need and whether it respects national ownership by part-

ner countries and promotes home-grown strategies (see section, Official development assistance needs to increase, Chapter 4). In Italy, for example, a Parliamentary Working Group on the Millennium Development Goals has been created to ensure that the MDGs are central to parliamentary debate and that members of parliament have access to current and relevant information on aid commitments by the government.

In the *Paris Declaration on Aid Effectiveness*,³³ both donor and partner countries agreed to enhance mutual accountability and transparency in the use of development resources. Low- and middle-income countries committed to strengthening the parliamentary role in national development strategies and budgets. Donor countries committed to providing timely, transparent and comprehensive information on aid flows to enable partner authorities to present comprehensive budget reports to their legislatures and citizens. Donors also committed to strengthening recipient country institutions and, in particular, parliaments.

In addition to strengthening legislative institutions in low- and middle-income countries, donor-country parliaments should share the information with recipient-country parliaments. In this way, parliaments can make their respective governments more accountable for development results. Finally, too many donors are sprinkling too little aid into too many different channels. Parliamentarians could ask that the ‘Three Ones’ approach (One strategic framework, One national AIDS authority, and One monitoring and evaluation mechanism) be adapted to the coordination and delivery of all HIV programmes, including those funded by international assistance.

BOX 14

Enhancing the role of parliaments in ensuring aid effectiveness³⁴

Recommendations for donor countries

- Parliaments should ensure that governments follow through on their 0.7% pledge (and on their pledge to help get antiretroviral drugs to where they are needed).
- Parliaments should give their countries’ development agencies a legislated mandate whereby parliament can better measure expectations against outcomes achieved.
- Evaluations of programmes funded by development agencies should be made available to recipient countries.
- To the greatest extent possible, aid policy should be non-partisan, as development requires consistent funding and multi-party support beyond the lifespan of a typical parliament.
- Donor countries should offer support to aid-recipient countries in ratifying and domesticating international conventions, especially those concerning anti-corruption.

Recommendations for low- and middle-income partner countries

- Governments and parliaments should demand timely, transparent and comprehensive information on aid flows from all donors.
- Parliaments should defend their role in national development strategies and budget processes, and play their role effectively.
- Budget and finance committees should demand adequate time and resources to assess whether budget estimates are aligned with national poverty reduction strategies.
- Parliamentary committees should increase their outreach to citizens and civil society groups through public hearings and consultations, and evaluate the impact of development programmes on the poor and vulnerable.
- Parliaments should share experiences with one another and be open to considering new accountability systems that allow funds to be tracked and results to be monitored more effectively.

Hold the executive to its promises

Governments have adopted several international agreements that include promises relating to AIDS. **A particularly important role of members of parliament is that of holding their governments to these promises, all of which remain relevant even if the deadlines have not yet been met.**

Following are important commitments on HIV that parliamentarians should be aware of so that they can track progress and, if necessary, demand that their governments live up to their promises. In addition to the promises listed here, there are regional declarations such as the *Abuja Declaration and Framework for Action for the Fight against HIV/AIDS, TB and Other Related Infectious Diseases in Africa* (2001). At the African Union meeting in Abuja, Nigeria in May 2006, African leaders also made additional commitments to universal access.

Millennium Development Declaration (2000)

At the UN Millennium Summit in September 2000, presidents, prime ministers and other national leaders agreed to reduce poverty and improve lives, and issued the eight MDGs³⁵ – ranging from halving extreme poverty, to halting the spread of HIV and providing universal primary education, all by the target date of 2015.

We will have time to reach the Millennium Development Goals – worldwide and in most, or even all, individual countries – only if we break with business as usual. ...Success will require sustained action... And we must more than double global development assistance over the next few years. Nothing less will help to achieve the Goals.

– Former United Nations Secretary-General Kofi Annan

As a precursor to the *Declaration of Commitment on HIV/AIDS*, MDG 6 (Combat HIV/AIDS, malaria & other diseases) calls for countries to begin reversing the spread of HIV by 2015. Failure to meet this goal would adversely affect the world's progress on the other MDGs. The effects of HIV continue to frustrate efforts to reduce extreme poverty and hunger, to provide universal primary education, to reduce child mortality and to improve maternal health.

➔ *For more information, see: The Millennium Development Goals Report. United Nations. The report presents the most comprehensive figures available on progress made towards the achievement of the Millennium Development Goals (MDGs). The report and many other materials related to the MDGs can be accessed via www.un.org/millenniumgoals/*

Declaration of Commitment on HIV/AIDS (2001)

In June 2001, Heads of State and Government and representatives of 189 nations gathered at the first-ever Special Session of the United Nations General Assembly on HIV/AIDS. They unanimously adopted the *Declaration of Commitment on HIV/AIDS*,³⁶ acknowledging that the AIDS epidemic constitutes a “global emergency and one of the most formidable challenges to human life and dignity”.

The *Declaration of Commitment* envisions a global response to HIV that is grounded in human rights and gender equality, as well as recognition of the factors that increase vulnerability to HIV. Under its terms, success in the response to AIDS is measured by the achievement of concrete, time-bound targets, calling for careful monitoring of progress in implementing agreed-on commitments.

In adopting the 2001 *Declaration of Commitment on HIV/AIDS*, **countries made national commitments and obligated themselves to regularly report on their progress to the General Assembly. Countries are required to submit Country Progress Reports to the UNAIDS Secretariat every two years.**

In 2003, 103 Member States (55%) submitted Country Progress Reports to UNAIDS, based on the core indicators. In most cases, National AIDS Committees or equivalent bodies oversaw the compilation of the national report. Civil society was involved in the preparation of roughly two-thirds of the reports and people living with HIV were involved in just over half of them. In 2005, 135 Member States (72%) submitted Country Progress Reports.³⁷

Parliamentarians should participate in the preparation of the Country Progress Reports and encourage their governments to prepare such reports if they have not done so in the past. They should also ensure that all democratic tools and mechanisms are used for such important reporting, and that countries engage in a true review process, whereby lessons are learned and civil society is actively engaged.

- *The full text of the Declaration of Commitment can be accessed via <http://www.unaids.org/en/Goals/UNGASS/default.asp>.*
- *At the same address, see also a summary of the Declaration; the 2005 country progress reports on monitoring the declaration of commitment; the 2006 report of the Secretary-General, Declaration of Commitment on HIV/AIDS: five years later.*
- *New Guidelines on construction of core indicators, prepared to assist countries in preparing and submitting their progress reports, can be accessed via http://www.unaids.org/en/Goals/UNGASS/2008_UNGASS_Reporting_FAQ.asp*
- *At the same address, see also UNGASS Reporting FAQ, a list of frequently asked questions on indicators for UNGASS reporting.*

World Summit Outcome Document (2005)

Recognizing that “HIV/AIDS, malaria, tuberculosis and other infectious diseases pose severe risks for the entire world and serious challenges to the achievement of development goals”,³⁸ world leaders committed to a massive scaling-up of HIV prevention, treatment and care with the aim of coming as close as possible to the goal of universal access to treatment by 2010 for all who need it. This universal access goal was later expanded in the 2006 *Political Declaration* to include prevention, care and support.

- *The full text of the World Summit Outcome Document can be accessed via <http://www.un.org/summit2005/>*

Political Declaration on HIV/AIDS

In June 2006, UN Member States met in the General Assembly High Level Meeting on AIDS to review progress and renew their commitments made in the 2001 UNGASS on HIV/AIDS. Heads of State and Government, and representatives of States and Governments unanimously adopted the *Political Declaration on HIV/AIDS*, reaffirming the 2001 *Declaration of Commitment on HIV/AIDS* and the Millennium

Development Goals. The *Political Declaration* recognizes that, to mount a comprehensive response, “governments must overcome any legal, regulatory, trade and other barriers that block access to prevention, treatment, care and support”, as well as “promote and protect all human rights and fundamental freedoms for all”.

Heads of State and Government, and representatives of States and Governments agreed to set ambitious national targets **by end 2006**, including **interim targets for 2008**, that reflect the commitment towards the goal of universal access to comprehensive HIV prevention programmes, treatment, care and support by 2010. Despite this commitment, by the end of 2006, only 90 countries had provided target data.³⁹ In many countries, the universal access target-setting process has simply become an exercise for planning or expanding national AIDS plans, not for setting ambitious targets. Despite their commitment to achieving “universal access”, many countries continue to exclude certain key populations (both in setting the targets and in the targets themselves) or set under-ambitious targets.⁴⁰

The next comprehensive reviews of progress made in implementing the *Declaration of Commitment* have been set for 2008 and 2011. As mentioned above, parliamentarians should ensure that countries prepare such reports and include in their preparation civil society, persons living with HIV and parliamentarians.

Ensuring ... [universal access to treatment, prevention, care, and support by 2010] is critical to achieving the Millennium Development Goal of halting and beginning to reverse the spread of HIV among women, men and children by 2015. And it is a prerequisite for meeting most of the other Goals. We cannot win the fight for development if we do not stop the spread of HIV.

– UN Secretary-General Ban Ki-moon at the General Assembly review of the Declaration of Commitment on HIV/AIDS, 21 May 2007

➔ *A number of web sites are dedicated to tracking the most important international policy commitments on AIDS. They contain much useful information for parliamentarians, including information about national progress reporting, shadow reporting, etc. See, in particular: www.ungasshiv.org (for the 2001 Declaration of Commitment); www.ua2010.org*

(for the commitment to universal access by 2010); www.ua2010.org/index.php/en/g8_aids (for commitments made by the G8).

➔ *For more information on AIDS statements, commitments and declarations by governments and the UN, see also: (1) World AIDS Campaign (2005). Promises, promises ... Statements, commitments and declarations on HIV/AIDS since 2001; (2) World AIDS Campaign (2006). Asleep at the wheel? Five years of G8 promises on global health. Both documents are available via www.worldaidscampaign.info.*

Checklist 1

Basics for effective parliamentary oversight of the response to AIDS⁴¹

- Is there a parliamentary focal point for HIV – a sub-committee or full parliamentary committee on HIV or a multi-party, non-partisan committee on HIV?
- Is a multisectoral approach to HIV being taken within parliament? Do several committees integrate HIV into their work?
- Is there adequate institutional support and capacity to undertake effective oversight of HIV?
- Have effective partnerships been established with civil society organizations with research capacity and expertise and with HIV service providers who are in a position to comment with authority on government programmes?
- Does parliament engage with people living with, affected by, and most at risk of, HIV and effectively represent their voices?
- Is the budget process being used as a critical vehicle for HIV oversight?
- Are efforts being undertaken to strengthen the representation of women in parliament?
- Are efforts being undertaken to improve monitoring of aid effectiveness?
- Are members of parliament aware of the many HIV-related promises made by their governments and of the progress reports their governments have committed to preparing? Do they participate in the preparation of these reports?

CHAPTER 4

Ensuring predictable and sustainable financing

Summary

- Funding for the response to AIDS in low- and middle-income countries has increased, but financial resources continue to fall far short of what is needed to move towards universal access to prevention, care, treatment and support.
- Governments have made many commitments to increase funding for AIDS and for official development assistance (ODA), but few are meeting these commitments.
- Countries need to develop credible, costed, sustainable, evidence-informed AIDS plans as the basis for national budgetary allocations and international donor financing. They also need to make AIDS a priority in national budget allocations.
- However, without increased official development assistance, the goal of universal access cannot be met. Among other things, countries need to meet their long-standing commitments, whether for foreign assistance or domestic spending, fully fund the Global Fund to Fight AIDS, Tuberculosis and Malaria, and continue debt relief efforts.
- Parliamentarians have a crucial role to play in advocating increased funding, in the development and monitoring of national plans, and in ensuring that funds are well spent.

Why are leadership and action to ensure predictable and sustainable financing so important?

Financial resources have increased, but they continue to fall far short of what is needed

From 1996 until 2005, available annual funding for the response to HIV in low- and middle-income countries increased 28-fold, from US\$ 300 million to US\$ 8.3 billion. However, existing pledges, commitments and trends suggest the rate of increase may be declining, and bridging the gap between resource needs and resource availability remains a challenge. Resource needs are increasing for two main reasons: first, increasing numbers of people living with HIV are falling ill; second, spending is increasing as HIV programmes are expanding to serve more of those in need.

Resource requirements in 2007 were estimated to be US\$ 18.1 billion, while resources expected to be available for the same year were estimated at US\$ 10 billion. In the coming years, an effective response will depend on sustained growth in annual funding until the epidemic is stopped and reversed.⁴²

Current funding in perspective

Annual increases in AIDS funding since 2001 have been impressive. However, given the rapid spread of the epidemic, the overall amounts are disappointing. In 2005, the 148 countries classified as low- and middle-

income by the World Bank were home to 5.5 billion people, or 85% of the world's population. The estimated annual funding of US\$ 8.3 billion for the AIDS response that year included out-of-pocket spending by HIV-positive people and their households. In millions of cases, they were spending far beyond their capacity and being driven even deeper into poverty and debt, but still not receiving antiretroviral treatment (ART) and other basic services.

The funding estimates also included all expenditures spent within each country by the government, civil society organizations and private businesses, and all donations by bilateral and multilateral donors and international civil society organizations, including philanthropic foundations. That same year, the 22 high-income countries that are the main donors to development aid (and members of the OECD's Development Assistance Committee) were home to 879 million people, or 13.6% of the world's population. The money spent from all sources on providing those 879 million people with the full range of health services came to more than US\$ 3 trillion.⁴³

Much more needs to be done to meet the funding requirements

To meet the funding requirements, there must be action on two fronts. First, more money must be raised. Second, the national and international partners in the response to AIDS must stay on course and accelerate efforts to build countries' capacity to make better use of whatever money may be available.

Credible, sustainable AIDS plans are needed as the basis for national budgetary allocations and international donor financing

Poor coordination between different stakeholders in affected countries can impede effective spending. The problem can be compounded by weak institutions and regulatory policies, poor governance and, in some cases, corruption. UNAIDS and others have been promoting the 'Three Ones' principles.⁴⁴

BOX 15

What are the 'Three Ones'?

The internationally agreed 'Three Ones' principles call for the coordination of a national AIDS response around one agreed AIDS action framework, one national coordinating authority (including government, civil society, people living with HIV and the private sector) and one agreed country-level monitoring and evaluation system.

For more information, see the publications on the UNAIDS web site at
www.unaids.org/en/Coordination/Initiatives/three_ones.asp

National AIDS authorities and their partners should therefore develop or adapt prioritized and costed AIDS plans that are aligned with national development plans and are ambitious but feasible in terms of reaching their targets for universal access.

No credible, costed, evidence-informed, inclusive and sustainable national AIDS plan should go unfunded.⁴⁵

BOX 16

Key resources: The World Bank's AIDS Strategy & Action Plan (ASAP)

What is ASAP?

As a global technical assistance service, ASAP responds to country requests for support in developing well-prioritized, evidence-based, results-focused, costed AIDS strategies and action plans. ASAP is hosted by the World Bank on behalf of UNAIDS.

What does ASAP do?

AIDS specialists from UNAIDS, other UN organizations, non-UN institutions and local and international consultants undertake country- and regional-level technical support activities on demand. Countries at any level of national AIDS strategy-planning can request assistance, as well as peer reviews from ASAP. ASAP has also developed a scorecard-style tool (with guidelines) that countries (and parliamentarians) can use to assess their strategies.

For more information and to request ASAP services, see www.worldbank.org/ASAP.

HIV should be a priority in national budget allocations

A long-term effort to end AIDS depends on an increase in public expenditure by low- and middle-income countries. Domestic spending – estimated at US\$2.8 billion in 2006, or 31% of total available AIDS funding – has risen in recent years, but remains insufficient. Middle-income countries, in particular, can expand domestic spending on their AIDS responses. But low-income countries can also do their part. For example, African nations could fulfil the financing target of the 2001 *Abuja Declaration on HIV/AIDS, Tuberculosis and Other Related Infectious Diseases*. In that Declaration, they committed to allocating at least 15% of their annual budgets to improve the health sector, including those services relating to AIDS.

Official development assistance needs to increase

In low-income countries, official development assistance will continue to be the main source of AIDS financing.

Donor-country governments provide the bulk of the development aid that flows from higher-income countries to lower-income countries. The main donor countries are the 22 member countries of the Development Assistance Committee (DAC) of the OECD. Official development assistance

(ODA) is the term for development aid from DAC members. At the UN General Assembly in 1970, DAC members promised to spend 0.7% of their gross national income on ODA. However, only a small minority of countries have achieved this target. In 2005, DAC members renewed the promise at the G8 Summit at Gleneagles and elsewhere. They should quickly increase their ODA to meet the 0.7% target.

The Global Fund to Fight AIDS, Tuberculosis and Malaria should be fully funded

In addition, countries should fully fund **the Global Fund to Fight AIDS, Tuberculosis and Malaria**, established in January 2002 as an innovative funding mechanism to address three key global health crises in low- and middle-income countries. It funds programmes that have been approved by an international technical review panel of health and development experts. In country consultations held before the 2006 High Level Meeting on HIV/AIDS, many low- and middle-income countries, strongly supported by civil society and people living with HIV, called for full funding of the Global Fund to obtain the resources that countries need to scale up AIDS programmes.

BOX 17
Friends of the Global Fund

'Friends of the Global Fund' organizations have become important players in the political and public debate around the Global Fund in individual countries and regions. Today, Friends of the Global Fund exist in Europe (www.afmeurope.org), Japan (www.jcie.or.jp/fgfj/e/) and Africa (www.friends-africa.org). In the United States of America, Friends of the Global Fight (www.theglobalfight.org) is an active player. The Friends organizations are independent from the Global Fund. Their cause and mandate are to objectively accompany the Global Fund's work and to inform political decision-makers, media and the public about the development, need, results and impact of the Global Fund. The Friends groups have very close links to parliamentarians and national parliaments in their respective countries.

Funding needs to be stable and predictable

International funding for public health and development needs to be stable and predictable. Volatile funding flows from donors, often reflecting priorities that are not shared by national governments, make it difficult to implement national plans. Many countries are reluctant to include these uncertain future revenues as a basis for national planning.⁴⁶

To increase the certainty and sustainability of financing, donors should make multi-year financing commitments for HIV programmes. Donors must work to translate the ‘Three Ones’ from aspiration to reality by aligning their assistance with nationally led strategies and by actively supporting unitary national systems for monitoring and evaluation. In ramping up HIV support, donors should prioritize measures to build and sustain national capacity, helping countries to upgrade remuneration and conditions of service to prevent the loss of essential personnel and aiding countries in expanding the roles of all levels of health workers, household members, mid-level providers, community workers and people living with HIV.

Debt cancellation efforts should continue

In order to free up resources for the response to AIDS and other public health needs, efforts to cancel the debts of the most seriously affected countries, whether owed to national governments or to private or multilateral bodies, should continue.

Macroeconomic and fiscal frameworks should be adjusted to address AIDS

While recognizing the importance of promoting sustainability, maintaining macroeconomic stability and fostering growth, low-income countries report that excessively tight deficit reduction and inflation reduction targets constrain the hiring and retention of the doctors, nurses, community health-care workers, teachers and administrators who are needed to scale up. National governments should therefore initiate a transparent and inclusive dialogue with all stakeholders to ensure that fiscal space is created for AIDS spending as high-priority social expenditure within domestic budgets, and that macroeconomic and fiscal frameworks are adjusted to address the reality of AIDS.

HIV/AIDS and related diseases such as tuberculosis thrive on economic hardship, inequality and deprivation. The spread of HIV makes even more pressing the need for broad-based human development. More than ever, parliamentarians need to forge national, regional and international partnerships that address the constraints to development, whether these stem from gender inequality, budgetary shortfalls, adverse terms of trade or international debt.

– Members of Parliament Clavel Martinez (Philippines) & Elioda Tumwesigye (Uganda), 2005

The impact of AIDS should be included in national development and poverty reduction plans

National governments should ensure that the impact of AIDS is included in the core indicators for measuring progress in implementing national development and poverty reduction plans.

Absorptive capacity needs to be increased to ‘make the money work’

Increased government and donor allocations for AIDS, without improved capacity to spend, challenge the overall strength of health systems. In some countries, absorptive capacity is increasingly becoming the issue for AIDS spending, rather than availability of resources. For this reason, “the donor community should . . . invest in capacity building in the government system to ensure that the resources they inject into the government are utilised effectively and efficiently”.⁴⁷

The design of a country’s own funding mechanisms can improve absorption of nationally sourced funds, but often bilateral donors’ funds are more problematic. This is largely due to the conditions that bilateral donors often attach to their funds. Funding that restricts spending to certain activities can help ensure that those specific projects are supported, but such earmarking may clash with national priorities. This decreases flexibility for programme managers as they try to manage the flow of funds so that they serve countries’ own priorities. Once a credible and sustainable AIDS plan is in place, conditions on donor funding for national AIDS programmes should be reduced to those that relate to good governance, fiduciary safeguards and the effective use of these funds to achieve national objectives.

Much could be achieved with adequate resources

It has been estimated that the following could be achieved by 2010, *if* the funding requirements can be met, *if* adequate funding can be sustained, and *if* the national and international partners can adequately accelerate efforts to build countries’ capacity to make better use of available resources.⁴⁸

- Comprehensive HIV prevention, based on the characteristics of the epidemic in each country, including programmes to reduce risk behaviours by those at greatest risk of exposure to HIV, as well as all adults and youth; to prevent mother-to-child transmission; and to ensure safe blood supplies and injections.
- Treatment and care for 9.8 million people, including 80% of those in urgent need.
- Adequate support for all orphans and vulnerable children, including home support, schooling, health care and community support.
- Sufficient programme capacity (planning, administration, staff, etc.) and infrastructure (hospitals, health centres, laboratories, etc.) to support prevention, treatment, care and support.
- Sufficient numbers of appropriately trained nurses, doctors and other personnel to support the above.

What can parliamentarians do?

Hold your government to its promises

In 2001, at the United Nations General Assembly on HIV/AIDS, governments agreed that “the HIV/AIDS challenge cannot be met without new, additional and sustained resources”.⁴⁹ In the *Declaration of Commitment on HIV/AIDS*, Heads of State and Government, and representatives of States and Governments committed to, among other things:

- ensuring “that resources provided for the global response to address HIV/AIDS are substantial, sustained and geared towards achieving results” (paragraph 79);
- **by 2005**, reaching an overall target of annual expenditure on the epidemic of US\$ 7–10 billion in low- and middle-income countries, and taking measures to ensure that the resources needed are made available, particularly from donor countries and also from national budgets (paragraph 80);
- increasing and prioritizing national budgetary allocations for AIDS programmes (paragraph 82);
- urging the developed countries that have not done so to strive to meet the target of 0.7% of their gross national product for overall official development assistance (paragraph 83);
- without further delay, implementing the enhanced Heavily Indebted Poor Country (HIPC) Initiative and agreeing to cancel all bilateral official debts of HIPC countries as soon as possible (paragraph 87);
- calling for speedy and concerted action to address effectively the debt problem of least developed countries (paragraph 88);
- encouraging increased investment in HIV/AIDS-related research, in particular for the development of sustainable and affordable prevention technologies, such as vaccines and microbicides (paragraph 89);
- supporting the establishment of a global HIV/AIDS and health fund (paragraph 90).

In 2006, in the *Political Declaration on HIV/AIDS*, governments recognized that important progress had been made since 2001 in the area of funding, but also recognized that UNAIDS has estimated that US\$ 20–23 billion per annum is needed by 2010 to support rapidly scaled-up AIDS responses in low- and middle-income countries, and therefore committed themselves “to taking measures to ensure that new and additional resources are made available from donor countries and also from national budgets and other national sources” (paragraph 40). In addition, they:

- committed themselves “to providing additional resources to low- and middle-income countries for the strengthening of HIV/AIDS programmes and health systems and for addressing human resources gaps” (paragraph 36);
- committed themselves “to reducing the global HIV/AIDS resource gap through greater domestic and international funding” (paragraph 39);
- welcomed “the increased resources that are being made available through bilateral and multilateral initiatives, as well as those that will become available as a result of the establishment of timetables by many developed countries to achieve the targets of 0.7% of gross national product for official development assistance by 2015 and to reach at least 0.5% of gross national product for official development assistance by 2010, as well as (pursuant to the Brussels Programme of Action for the Least Developed Countries for the Decade 2001–2010) 0.15–0.20% for the least developed countries no later than 2010”, and “urged those developed countries that have not yet done so to make concrete efforts in this regard in accordance with their commitments” (paragraph 39);
- committed themselves to “supporting and strengthening existing financial mechanisms, including the Global Fund to Fight AIDS, Tuberculosis and Malaria, as well as relevant United Nations organizations, through the provision of funds in a sustained manner, while continuing to develop innovative sources of financing” (paragraph 41).

In addition, countries have made other important commitments. These include the Group of Eight commitments to increase official development assistance; the European Union pledge to commit an average of 0.56% of national wealth for aid by 2010 and 0.7% by 2015; the Monterrey Consensus; and the *Abuja Declaration on HIV/AIDS, Tuberculosis and Other Related Infectious Diseases*, in which African nations committed to spending 15% of their budgets on health.

Actively participate in setting and supporting national priorities

- Ensure that national AIDS authorities and their partners develop or adapt a prioritized, costed and evidence-based AIDS plan that is aligned with national development plans and that is ambitious but feasible in terms of reaching its target of universal access to prevention, care, treatment and support by 2010.
- Take an active role in this process and ensure that civil society, including people living with HIV and members of vulnerable communities, can meaningfully participate in all aspects of the development, implementation and evaluation of the plan.

- Ensure that the impact of AIDS is included in the core indicators for measuring progress in implementing national development and poverty-reduction plans, and actively participate in the development, revision and monitoring of these plans.
- Call for, and participate in, a transparent and inclusive dialogue with all stakeholders to ensure that fiscal space is created for AIDS spending as high-priority social expenditure.

BOX 18

A best practice example of leadership and action: The development of the HIV & AIDS Strategic Plan for South Africa (2007–2011)

In 2006, the South African National AIDS Council mandated the Health Department to lead a process of developing a new five-year national strategic plan on AIDS. The plan was developed through an intensive and inclusive process of drafting, collection and collation of input from a wide range of stakeholders, including parliamentarians. Its primary aims are to:

- reduce the rate of new infections by 50% by 2011;
- reduce the impact of AIDS on individuals, families, communities and society by expanding access to appropriate treatment, care and support to 80% of all HIV-positive people and their families by 2011.

The interventions needed to reach these goals are structured under four key priority areas: prevention; treatment, care and support; research, monitoring and surveillance; and human rights and access to justice. The plan sets out a clear framework for ongoing monitoring and evaluation. Ambitious but realistic targets have been set for each of the identified interventions. Preliminary costing of the main elements is included and a commitment has been made to raise funding from government, business and the various development partners.

For a copy of the plan, see <http://www.doh.gov.za/docs/misc/stratplan-f.html>

Advocate greater domestic and international AIDS spending

- **Advocate greater domestic and international AIDS spending in order to ensure countries' access to predictable and long-term financial resources.**
- **Call on your national government and on international donors to significantly increase the financial resources available for AIDS by:**
 - fulfilling existing commitments;
 - making additional, predictable commitments, as part of a comprehensive, long-term funding plan that will deliver sufficient resources for universal access to be achieved;
 - making long-term, predictable commitments to fully finance the Global Fund to Fight AIDS, Tuberculosis and Malaria and pay their fair share of its resource needs;

- supporting other innovative financing mechanisms, such as the establishment of an International Finance Facility, the international solidarity contribution on airline tickets and various debt relief and debt conversion mechanisms, for both public-sector and nongovernmental providers of AIDS programmes.
- **Call on international donors and partner countries to adhere to the ‘Three Ones’ principles and implement the recommendations of the Global Task Team on Improving AIDS Coordination among Multilateral Institutions and International Donors⁵⁰** for the efficient and effective use of financial resources, including through alignment with national priorities.
- **Call for the reduction of conditions on donor funding** for national AIDS programmes to those that relate to good governance, fiduciary safeguards and the effective use of these funds to achieve national objectives.
- **Advocate just and effective allocation of resources.** HIV is highly stigmatized in many countries, often affecting marginalized populations such as people who use drugs, sex workers and their clients, men who have sex with men, migrants and mobile populations. Where necessary, advocate that both donors and governments overcome their reluctance to commit resources to help people whose activities may be subject to social disapproval.
- **Call on the private sector to increase its contribution to the response to AIDS, in cash or in kind.**

BOX 19

An example of leadership and action: Canadian Parliamentary Committee calls for doubling of national AIDS funding

In May 1998, the Canadian Federal Government announced the Canadian Strategy on HIV/AIDS (CSHA). This included an annual funding allocation of \$42.2 million Canadian dollars. In 2003, the Canadian Federal Department of Health (Health Canada) was undertaking a five-year review of the Strategy.

The Standing Committee on Health of the House of Commons agreed to examine the CSHA in response to concerns about annual funding expressed by the major nongovernmental partners. They questioned the fact that funding had remained static over the last 10 years of the AIDS epidemic.

To gain greater understanding of the federal government’s responsibilities and actions, the Committee held meetings with key governmental and nongovernmental partners. In June 2003, it released its report, *Strengthening the Canadian Strategy on HIV/AIDS*. In the report, it recommended that the federal government “increase the total funding for the renewed federal Canadian Strategy on HIV/AIDS to \$100 million annually”; and that “this increased funding be contingent on the establishment of five-year measurable goals and objectives for decreasing the number of new cases

each year". At least in part because of the report, the federal government did indeed make a decision to double funding for AIDS gradually over a five-year period.

However, to a large extent, increased funding for Canada's AIDS strategy has not, in fact, led to enhanced support for community-based responses and the kinds of initiatives recommended in the *International Guidelines on HIV/AIDS and Human Rights*, including attention to legal/policy aspects of an 'enabling environment' and human rights concerns. As discussed in Chapter 3, this highlights the fact that parliamentarians need to maintain a constant watchdog function to ensure that increased funding for AIDS is used to support evidence-informed policy and interventions that respect, protect and promote human rights.

For more information and a copy of the report, see the Parliamentary Internet: www.parl.gc.ca

BOX 20

AIDS budget recommendations for members of parliament

From 14 to 16 November 2001, AWEPA organized, in cooperation with the United Nations Children's Fund (UNICEF), a conference entitled Parliament and the AIDS Budget, in Rustenburg, South Africa. Participants made the following recommendations, among others.

Budgets must reflect the high priority of addressing HIV

- Parliamentarians need to be empowered to make informed policy choices when deciding what amounts are to be (re)allocated and to which priority areas.
- Parliamentarians should analyse the budget from an AIDS perspective, after listening to the needs of their constituents, and make appropriate adjustments.
- Parliamentarians need to ensure that monitoring mechanisms are in place to guarantee that resources reach intended targets.

Parliaments must be strengthened to influence budget priorities

- Parliamentarians should be in a position (if needed, after parliamentary reform) to debate and modify the budget before approval, to ensure that the AIDS response gets priority.
- It is very important to ensure that resources to address AIDS-related challenges reach the level of communities, without party-political discrimination.
- Patriarchal systems in society need to be reversed to stop the spread of HIV, and members of parliament can take a leadership position in this.
- Legislation and resources are needed to protect the rights of people living with HIV and children orphaned by AIDS.

Parliamentarians need capacity-building on AIDS-related issues

- Parliamentarians need informational workshops and information materials in local languages on AIDS and on actions that are needed to reach universal access to prevention, treatment, care and support.
- Parliamentarians need to be empowered to interact with people in communities and assist them in accessing funds available for initiatives relating to AIDS.

Parliamentarians should consider the following in budgeting decisions

- Greater budget allocations for training of teachers and health workers
- Education on HIV, AIDS and life skills as part of school curricula
- Strengthening of prevention programmes
- Projects addressing economic empowerment of youth and women

- Projects that address violence against women and involve men as partners
- Initiatives that promote care of orphans within their own community
- Protection of orphans to ensure that they inherit the property of their deceased parents.

The AIDS epidemic calls for a collaborative approach: the international community must take up its responsibility

- International assistance should be increased to provide additional resources for the AIDS response.
- The debt burden of countries should be reduced and linked to enhanced accountability, freeing up resources for AIDS-related initiatives and creating availability of drugs at affordable prices.

For more information, see the AWEPA web site at www.awepa.org.

PART II

*Moving towards universal access
to HIV prevention, treatment,
care and support:
What parliamentarians can do*

Introduction

Over 25 years into the HIV epidemic, more than “half of the countries submitting reports to UNAIDS acknowledged the existence of policies that interfere with the accessibility and effectiveness of HIV-related measures for prevention and care”.⁵¹ This needs to change if countries want to meet the goal of universal access to prevention, care, treatment and support.

This second part of the Handbook deals with some of the central legal and policy issues that have to be addressed as countries scale up HIV prevention, treatment, care and support programmes. This will **assist parliamentarians in becoming leaders, taking action and making decisions on specific HIV-related law and policy-reform issues.**

It will help parliamentarians play their rightful role in overcoming legal, regulatory or other barriers to HIV prevention, treatment, care and support, and in eliminating discrimination against, and ensuring the human rights of, people living with HIV and members of vulnerable groups, as called for by the United Nations General Assembly 2006 *Political Declaration on HIV/AIDS*.

CHAPTER 5

HIV testing and counselling

Summary

Why your leadership and action on HIV testing and counselling are so important

- Vastly expanded access to voluntary, affordable and high-quality HIV testing and counselling is essential for an effective global response to HIV, and is both a public health and a human rights imperative.
- The most important actions countries need to take to increase access to high-quality HIV testing and counselling include: (1) examining whether provider-initiated HIV testing and counselling should be implemented and whether the necessary prerequisites for implementation exist; (2) ensuring that HIV testing is only undertaken with counselling, informed consent, and confidentiality; (3) scaling up client-initiated voluntary counselling and testing and meeting the needs of vulnerable populations; (4) creating an enabling environment for HIV testing and counselling; and (5) prohibiting mandatory or compulsory HIV testing.

What you can do

- Parliamentarians have a crucial role to play when it comes to facilitating efforts to scale up access to HIV testing and counselling. Priorities for action include providing leadership by raising awareness of the potential benefits of HIV testing and counselling; publicly taking an HIV test and disclosing your status; undertaking legislative and policy reform to ensure that scaling-up of HIV testing and counselling is linked to other HIV services and human rights protections, and that policies and legislation requiring or authorizing mandatory or compulsory HIV testing are repealed; and advocating increased funding for a comprehensive package of interventions, including HIV testing and counselling.

Why are leadership and action on HIV testing and counselling so important?

Expanding access to HIV testing and counselling is an urgent priority

One of the conditions for achieving the aim of universal access to comprehensive HIV services is an expansion of HIV testing and counselling. Only a small minority of persons living with HIV in low- and middle-income countries know their HIV status.⁵² In many countries, access to HIV testing and counselling remains limited. Many high-income countries also estimate that many people living with HIV are not aware of their HIV status.

Scaling up access to HIV testing and counselling is likely to have many benefits, **as long as those testing positive can benefit from treatment (including antiretroviral therapy – ART), have access to evidence-informed prevention measures that enable them to reduce the risk of transmission to their partners, and are protected from stigma, discrimination and violence through a supportive social and legal environment.**

In some settings, new approaches to HIV testing and counselling are needed

In recent years, it has been internationally recognized that, in addition to the traditional model of client-initiated voluntary counselling and testing (VCT), new approaches to HIV counselling and testing should be implemented in more settings, and on a much larger scale.

Currently, many opportunities for diagnosing and counselling individuals at health facilities are being missed. Diagnosis and access to HIV-related services could be facilitated if so-called provider-initiated HIV testing and counselling (PITC) was introduced. With such an approach, HIV testing and counselling would be offered and recommended in health facilities for all patients, irrespective of epidemic setting, whose clinical presentation might result from underlying HIV infection. Testing and counselling would also be offered as a standard part of medical care for all patients attending health facilities in countries with generalized HIV epidemics. These services would be more selectively offered in countries with concentrated and low-level epidemics.

➔ *See Box 30 in Chapter 7 for the definition of ‘generalized’, ‘concentrated’ and ‘low-level’ epidemics.*

Client-initiated VCT services also need to be scaled up

In recent years, the debate about scaling up access to HIV testing and counselling has focussed on provider-initiated testing and counselling in formal health settings. But client-initiated voluntary counselling and testing services that are responsive and sensitive to the communities served also need to be adequately supported by resources as well as promoted and scaled up.

Scaling up access to client-initiated voluntary counselling and testing is particularly important because large numbers of people do not use formal health services and may need other ways of gaining access to HIV testing and counselling, especially if they live in rural areas poorly served by the health-care system, are mobile, or belong to vulnerable communities who face stigma and discrimination in health settings.

HIV testing should not be undertaken without counselling, informed consent, and confidentiality

As countries expand access to HIV testing and counselling and consider introducing provider-initiated testing and counselling, it will be more important than ever to ensure that HIV testing is undertaken with counselling, informed consent, and confidentiality.

In the early years of the HIV epidemic, aggressive calls for punitive, forcible testing sparked widespread concern about the effects of such strategies on individual rights and the spread of the epidemic. Eventually, members of affected communities and public health professionals recognized that HIV testing must be voluntary and that informed choice was central to creating a climate of confidence and trust between the person being tested and service providers. Three principles of HIV testing (the ‘Three Cs’) were established as norms of ethical and sound practice:

- *counselling* and information about HIV before and after the test
- *consent* to be tested given in an informed, specific and voluntary way by the person to be tested
- *confidentiality* regarding test results and the act of seeking a test.

In recent years, some proponents of more routine approaches to testing have dismissed the ethical and human rights requirement that testing be voluntary. However, arguments in favour of models of HIV testing that eliminate or minimize specific, informed consent and counselling do not adequately take into account the link between these elements and human rights.

- Informed consent protects the human right to security of the person as well as the right to receive information. Pre-test counselling contributes to the protection of these same human rights. Post-test counselling also imparts information to which people have a right. Confidentiality regarding test results and the act of seeking an HIV test is part of protecting and respecting the right to privacy.⁵³
- Beyond the components of the testing process itself, governments have a responsibility to ensure that HIV testing is not offered or provided in a way that discriminates against any person or group of people.
- Finally, the right to be free of discrimination and the right to security of the person also require that, in setting HIV-testing policy and overseeing its practice, governments take into account the outcomes of HIV testing for people and do all they can to prevent human rights violations associated with HIV testing.

In order to make it feasible for health-care providers to offer HIV testing to all their patients, in some settings it may be justified to relax, to some extent, pre-test counselling requirements. Human rights and public health concerns do not require that cumbersome procedures for pre-test counselling be used. **However, they require that persons can seek and receive sufficient information to enable them to give informed and truly voluntary consent to testing, regardless of whether they are routinely offered an**

HIV test in a health-care setting or whether they initiate HIV testing themselves. They also require that people receive post-test counselling and that confidentiality of test results and of the act of seeking a test are guaranteed.

In countries that adopt a so-called ‘opt-out approach’ to provider-initiated testing and counselling (whereby people are tested unless they clearly opt out and refuse to be tested), great care will have to be taken to ensure that this will not result in a greater number of people being tested without their informed and voluntary consent. Concerns about the potential coercion of patients and adverse outcomes of disclosure underscore the importance of adequate training and supervision of health-care providers and the need for close monitoring and evaluation of expanded HIV testing and counselling programmes.

HIV testing cannot be implemented in isolation

HIV testing is not a goal in itself and should always be linked to prevention, care and support for every individual tested, while ensuring that access to treatment, where required, is as rapid as possible. Consequently, the efficacy of testing policies and programmes is, in turn, co-determined also by the availability of effective prevention, care, treatment and support programmes. This means that efforts to scale up access to HIV testing and counselling must be linked to efforts to scale up access to ART and to evidence-informed prevention.

Increasing access to HIV testing and counselling must also go hand in hand with much greater investment in real human rights protection – in practice, and not just on paper – from HIV-related discrimination and abuse, particularly for women, children and adolescents, sex workers, men who have sex with men, people who use drugs, and prisoners.

BOX 21

Key resources on HIV testing and counselling

- WHO & UNAIDS (2007). *Guidance on provider-initiated HIV testing and counselling in health facilities*. Geneva: WHO.
- UNAIDS Reference Group on HIV and Human Rights (2007). *Statement and recommendations on scaling up HIV testing and counselling*. Geneva: Reference Group.
- UNAIDS & WHO (2004). *Policy statement on HIV testing*. Geneva: UNAIDS.
- WHO Regional Office for Africa (2005). *Regional HIV/AIDS Voluntary Counselling and Testing Guidelines*. Brazzaville: WHO.
- WHO Regional Office for South-East Asia (2004). *Voluntary HIV counselling and testing: manual for training of trainers, parts 1 & 2*. New Delhi: WHO.

What parliamentarians can do

Provide political leadership on HIV testing and counselling

In many countries, only a small proportion of persons living with HIV know their HIV status, at least in part because of the stigma related to HIV testing. Parliamentarians can help lessen that stigma and encourage people to take the test.

- Speak out in public about HIV, promote the rights of people living with HIV, and talk about the benefits of knowing and disclosing one's HIV status.
- Publicly take an HIV test, **disclose your HIV status**, and encourage others to do the same.
- Speak out against ineffective measures such as mandatory or compulsory HIV testing, and instead advocate HIV testing policies and practices that are evidence-informed and respect peoples' rights.

BOX 22

An example of leadership and action: Members of parliament publicly take an HIV test

Minister for Culture David Lammy, MP for Tottenham (UK), took a public HIV test in his constituency on World AIDS Day 2006, to highlight the need for testing among African communities. "The African community in Britain is a group particularly affected by the virus, but due to significant social stigmas around getting tested, far too many people don't feel they can," he said.⁵⁴

On 18 December 2006, the Chief Minister of Andhra Pradesh (India), Dr Y.S.R. Reddy, along with the Speaker of the Assembly, eight cabinet ministers and 70 legislators, publicly took an HIV test in the State Legislative Assembly.⁵⁵

Create a supportive policy and legal framework for HIV testing and counselling

Many countries currently do not have the supportive social, policy and legal framework necessary to maximize positive outcomes of HIV testing and counselling and minimize potential harms to patients.⁵⁶ Decisions on how best to expand HIV testing and counselling in a particular country will, therefore, have to depend upon an assessment of the situation in the country. Where there are high levels of stigma and discrimination or low capacity of health-care providers to implement HIV testing under the conditions of informed consent, confidentiality and counselling, adequate resources must be devoted to addressing these issues **prior to implementation of expanded HIV testing and counselling**.⁵⁷

In addition, scaling up HIV testing and counselling will require significant human resources. A redistribution of health-worker responsibilities (task-shifting) in health facilities may help to overcome chronic staff shortages in some settings. This may entail identifying appropriately skilled lay personnel who can receive training and remuneration to carry out HIV testing and counselling activities under the supervision of health-care professionals with more specialized expertise. People living with HIV, AIDS service organizations and other community-based organizations and civil society groups can provide an important source of skilled lay personnel for delivery of testing and counselling services, for patient-tracking and referral services and for monitoring and evaluation. In some settings, expanding the types of health workers who are authorized to carry out HIV testing and counselling may require amendments to laws and regulations.

Parliamentarians should take the following steps.

- Ensure that governments assess the situation in-country, and prior to and during implementation of expanded testing and counselling, ensure that the following prerequisites for expanded testing and counselling are in place.
 - access to HIV prevention, care and support services
 - a reasonable expectation that ART will become available in the near future within the framework of a national plan to achieve universal access to treatment
 - sufficient capacity of health-care providers to implement client- and provider-initiated HIV testing and counselling under the conditions of informed consent, confidentiality and counselling
 - programmes to protect people from stigma and discrimination.
- Demand that countries cost, budget and implement national programmes that would secure legal and human rights protections for people living with, affected by, and at risk of, HIV. These programmes should include legal reform and legal support services, 'know your rights' campaigns, campaigns against violence towards women, and other initiatives to help create a supportive social, legal and policy environment in which people can seek HIV testing and counselling with adequate protections against stigma, discrimination and other human rights abuses.
- Review and, if necessary, amend policies, laws and regulations in order to allow: (a) task-shifting in health facilities; and (b) lay personnel to carry out HIV testing, counselling, monitoring and evaluation, after receiving adequate training.

BOX 23**What do the *International Guidelines on HIV/AIDS and Human Rights* say about HIV testing?**

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” (paragraph 20b);
- “whenever possible, that pre- and post-test counselling be provided in all cases” (paragraph 20c);
- “that HIV and AIDS cases reported to public health authorities for epidemiological purposes are subject to strict rules of data protection and confidentiality” (paragraph 20e);
- “that information relative to the HIV status of an individual be protected from unauthorized collection, use or disclosure in the health-care and other settings and that the use of HIV-related information requires informed consent” (paragraph 20f).

Prohibit compulsory and mandatory testing

Mandatory and compulsory HIV testing occurs in many countries and contexts.⁵⁸

- In India, the State Government of Goa has proposed mandatory premarital testing, despite opposition by women’s groups and AIDS activists who recognize that empowering women to negotiate condom use and discuss HIV with their partners and spouses is more important for their protection, before and during marriage.
- In Saudi Arabia, testing is mandatory for foreign workers, who are then confined to locked hospital rooms and deported if found to be HIV-positive.
- Many countries continue to apply mandatory HIV testing to people in certain institutions, such as the military or prisons, or those undergoing certain evaluations, such as medical examinations for insurance.
- Over 60 countries require HIV testing prior to entry for migrants, particularly those requesting a residence or work permit.⁵⁹

International agencies working on HIV and public-health authorities reject compulsory or mandatory testing as unethical and a violation of human rights and as ineffectual for public health.⁶⁰ The one exception is HIV screening of donated blood prior to transfusion and before all procedures involving transfer of bodily fluids or body parts, such as artificial insemination, corneal grafts and organ transplant. In these special cases only, mandatory HIV testing is recommended and testing is commonly required by national HIV policies, often legislatively. Therefore, parliamen-

tarians should review their country's current policy and legislation and, if necessary, amend or repeal laws requiring or authorizing mandatory or compulsory HIV testing of certain populations or in certain circumstances, with the exception of HIV screening of donated blood prior to transfusion and before all procedures involving transfer of bodily fluids or body parts.

BOX 24

An example of problematic legislation on HIV testing

Article 17 of the *Model Legislation on HIV/AIDS for West and Central Africa* provides for the following:

- No one shall be compelled to undergo an HIV test without his/her written consent. Such consent shall be required of the person concerned if s/he is of age or by his/her parent or guardians if the person is a minor or is mentally disabled.
- The government shall take all the necessary measures to ensure the provision of VCT services and encourage their use.
- In the event of donations of organs, cells or blood, the consent to undergo an HIV test is legally assumed when a person willingly or unwillingly agrees to give his blood, organ or cell for transfusion, transplant or research.

Article 18 prohibits mandatory HIV testing, but creates a number of specific exceptions that are not justified. The article states: An HIV test shall not be a requirement for the following: securing a job, admission to school or universities, access to accommodation, entry/stay in a country or the right to travel, access to medical care or any other service. However, this prohibition is revoked when:

- a) a person is indicted for HIV infection or attempt to infect another person with HIV;
- b) a person is indicted for rape;
- c) determining the HIV status is necessary to solve a matrimonial conflict;
- d) a pregnant woman undergoes a medical check-up.

Such exceptions should be removed. For example, **while HIV counselling and testing should be routinely offered and recommended to all pregnant women, they should never be tested without their informed consent.** Legislating mandatory HIV testing of accused rapists should be undertaken with caution. HIV testing may not provide timely or reliable information about the rape survivor's risk of contracting HIV infection. Presumably, the goal of mandatory testing of accused sexual offenders is to provide an opportunity for survivors who may have been exposed to HIV to receive post-exposure prophylaxis (PEP). The law should ensure that all victims of sexual offences be given access to PEP and counselling, regardless of whether alleged sexual offenders are tested for HIV. Finally, the resolution of a matrimonial conflict will rarely, if ever, require mandatory HIV testing.

With respect to HIV testing in the context of the workplace, the *Code of Practice on HIV/AIDS and the world of work* prohibits screening for purposes of employment, promotion or training, and stipulates that HIV testing should not be carried out at the workplace.

Hold your government to its promises

In the *Declaration of Commitment* (2001), countries committed themselves to the following HIV testing and counselling target. “By 2005, ensure that a wide range of prevention programmes ... is available in all countries ... including ... expanded access to voluntary and confidential counselling and testing ...” (paragraph 52).

In 2006, in the *Political Declaration on HIV/AIDS*, Heads of State and Government, and representatives of States and Governments renewed their commitment to “intensifying efforts to ensure that ... in all countries ... expanded access to voluntary and confidential counselling and testing [is available] ...” (paragraph 22).

Advocate increased funding for a comprehensive package of interventions, including HIV testing and counselling

Countries need to anticipate the additional resources required for scaling up access to HIV testing and counselling, including for training, clinical infrastructure and the purchase of commodities such as HIV test kits and other clinical supplies. In addition, they **need to ensure that efforts to scale up access to HIV testing and counselling are coordinated and integrated with efforts to scale up access to prevention, treatment and care.**

Parliamentarians should:

- advocate increased funding for HIV testing and counselling, while emphasizing that these resources should not be diverted from other needed services;
- ensure that increased resources for HIV testing and counselling are matched with greater resources for a comprehensive package of interventions, including treatment (including ART), care and support for people testing positive, evidence-informed prevention measures, and programmes to secure legal and human rights protections for people living with, affected by, or vulnerable to, HIV;
- support the inclusion of adequate referral, patient-tracking and follow-up mechanisms in HIV testing and counselling programmes, to ensure that tested patients receive prevention, treatment, care and support, as appropriate;
- ensure that monitoring and evaluation form an essential and ongoing part of programmes to expand HIV testing and counselling.

Checklist 2

HIV testing and counselling – key issues for parliamentarians

This list contains key considerations that should inform the development of sound public policy in this area. Check here whether your country conforms to international good practice.

- In countries implementing provider-initiated testing and counselling, are key stakeholders, including parliamentarians, civil society groups and people living with HIV, being consulted and included in a process to plan an implementation strategy? Are the prerequisites for provider-initiated testing and counselling in place?
- Are efforts being undertaken to increase access to client-initiated voluntary HIV counselling and testing?
- Are specific efforts being made to increase access to client-initiated voluntary counselling and testing for key populations, particularly through innovative approaches such as services delivered through mobile clinics, in other community settings, through harm reduction programmes or through other types of outreach?
- Does policy and legislation require specifically that informed consent (with sufficient information before testing and post-test counselling) be obtained from individuals before they are tested for HIV?
- Does the law and policy prohibit screening of job applicants and workers at the workplace on the basis of an HIV test or any requirement of an applicant or worker to disclose HIV status or regular use of medication?
- Have adequate resources been set aside for the training and ongoing supervision of health-care providers?
- Are efforts to increase access to HIV testing and counselling (in particular, introduction of provider-initiated testing and counselling) closely monitored and evaluated?
- Are efforts to scale up access to (1) HIV testing and counselling, and (2) antiretroviral therapy and evidence-informed prevention (including promotion and provision of male and female condoms and access to sterile needles and syringes and other harm reduction interventions for people who inject drugs) coordinated and integrated?
- Have referral, patient-tracking and follow-up mechanisms been built into HIV testing and counselling programmes, to ensure that tested patients receive prevention, treatment, care and support, where appropriate?
- Are efforts made to ensure that a supportive social, policy and legal framework is in place to avoid discrimination and even violence against patients testing positive?
- Are there regulatory standards for health professionals and other testing providers, with clear guidelines for the protection and respect of human rights, and with measures for discipline if they do not meet those standards?
- Has the country costed, budgeted and implemented a national programme to secure legal and human rights protections for people living with, affected by, or vulnerable to, HIV?
- Are laws and policies against discrimination on the basis of HIV status, risk behaviour and gender in place, monitored and enforced?
- Does policy or legislation provide for HIV screening of donated blood prior to transfusion, and before all procedures involving transfer of bodily fluids or body parts?
- Do policies, laws and regulations allow (a) task-shifting in health facilities and (b) lay personnel to carry out HIV testing and counselling, after receiving adequate training?

CHAPTER 6

Eliminating stigma and discrimination

Summary

Why your leadership and action on stigma and discrimination are so important

- Stigma and discrimination constitute one of the greatest barriers to dealing effectively with the HIV epidemic. Although national governments made commitments to take action against stigma and discrimination, many have failed to do so.
- Stigma and discrimination in the workplace continue to raise particular issues.

What you can do

- Parliamentarians have a crucial role to play in fighting stigma and discrimination by, among other things: (1) understanding and speaking out against stigma and discrimination; (2) meeting publicly with people living with HIV and members of most-at-risk populations; (3) supporting the development of a strong movement of people living with HIV; (4) providing a visible example by declaring their own HIV-positive status, if applicable; (5) securing policy and legal change to eliminate discrimination and provide privacy protections; and (6) ensuring that countries develop prioritized, costed, and longer-term plans to address stigma and discrimination, participating in their development, and calling for adequate funding for their implementation.

Why are leadership and action on stigma and discrimination so important?

Stigma and discrimination remain formidable obstacles to effective responses to HIV

Because of its association with behaviours that may be considered socially unacceptable by many people, HIV infection is widely stigmatized.

People living with the virus are frequently subject to discrimination and human rights abuses: many have been thrown out of jobs and homes, rejected by family and friends, and some have even been killed.

Together, stigma and discrimination constitute one of the greatest barriers to dealing effectively with the epidemic. They discourage governments from acknowledging or taking timely action against HIV; they deter individuals from finding out about their HIV status and their rights; and they inhibit those who know they are infected from sharing their diagnosis, taking action to protect others and seeking treatment and care for themselves.

Discrimination in the workplace presents particular challenges

Of the more-than-33 million people living with HIV worldwide at the end of 2007, the vast majority are aged 15–49 and therefore of working age. This fact has critical implications for businesses and national economies, as well as for individual workers and their families.

Stigma and discrimination can threaten the fundamental rights of employees living with HIV. Some employers harbour misconceptions about the routes of HIV transmission and fear increased HIV transmission within their workplace, while others fear increased costs, including health-care and insurance costs, as well as the expense of accommodating employees living with HIV. Most persons living with HIV can work normally or with minimal accommodation. Yet many employers insist on HIV testing to screen potential employees during the hiring process, as a basis for training or promotion, and as a pretext for eliminating HIV-positive employees from their workforce.

The fear of HIV in the workplace is counterproductive because it maintains stigma and discrimination, which, in turn, reduce receptivity to prevention messages and inhibit the uptake of opportunities for HIV testing, counselling and even treatment.

BOX 25

Key resources: The ILO Code of Practice on HIV/AIDS and the World of Work

The International Labour Organization has drawn up a *Code of Practice on HIV/AIDS* for the workplace, recognizing that the workplace – public and private, formal and informal – has a vital role to play in limiting the spread of HIV and the impact of the epidemic. The *Code of Practice* provides guidelines with which countries can develop policies and interventions at national, community and company levels. The code is based on consensus between employers, employees and government, and recommends that all policies related to the workplace be developed using similar collaborative processes. The code has been translated into over 40 languages and has been a reference point for laws and policies in over 70 countries.

In order to reinforce the code and strengthen the workplace response, the ILO has begun work towards the adoption of a Recommendation on HIV/AIDS and the world of work. A first discussion will be held during the International Labour Conference in June 2009, and the new legal standard is expected to be adopted as the outcome of a second discussion in June 2010. ILO Recommendations provide guidance for States and for employers' and workers' organizations, among others, and form a basis for the ILO's advocacy for workers' rights and its technical cooperation with Member States. The Governing Body of the ILO may require reports from Member States periodically on the measures they are taking to implement Recommendations.

The *ILO Code of Practice* and additional materials, including a database of national instruments related to HIV and the world of work, can be found via www.ilo.org/aids. For more information, see also the section on the ILO in Annex 4.

Privacy protections are often not adequate

Because of the existence of discrimination, the sensitivity surrounding HIV-related information is higher than for other medical data. Disclosure of information about HIV can reveal intimate details about an individual's health status and other personal information that an individual may wish to keep private. Disclosures of HIV status can damage the privacy of persons living with HIV and have other negative consequences such as stigma, discrimination, violence and social isolation. Disclosure may also lead to serious economic harm, including loss of employment, insurance or housing. It therefore follows that, in the workplace, job applicants or workers should not be required to disclose HIV-related personal information for any purpose. On the other hand, disclosure of information about HIV may be required in certain limited circumstances, such as for the provision of appropriate medical care. Hence, countries need to develop laws and policies that balance the need for disclosure of HIV information with the protection of the privacy and autonomy of individuals with respect to their HIV status.

➔ *See Box 27 for an example of particularly well-crafted provisions about privacy and disclosure of information, as well as a good and a bad example of partner notification provisions.*

What parliamentarians can do

Take action against stigma and discrimination and support people living with HIV

As discussed in greater detail in Chapter 1, parliamentarians have a crucial role to play in fighting stigma and discrimination by, among other things:

- speaking out against stigma and discrimination and demanding that governments take action (e.g. by rolling out campaigns on tolerance, compassion, non-discrimination, gender equality, and the rights of people with HIV and members of key at-risk populations);
- meeting publicly with people living with HIV and members of key at-risk populations;
- supporting the development of a strong movement of people living with HIV;
- providing a visible example by declaring their own HIV-positive status, if applicable.

Hold your government to its promises and secure policy and legal change to eliminate discrimination and provide privacy protections

In the *Declaration of Commitment* (2001), countries committed themselves to the following stigma- and discrimination-reduction targets:

- By 2003, enact, strengthen or enforce, as appropriate, legislation, regulations and other measures to eliminate all forms of discrimination against, and to ensure the full enjoyment of all human rights and fundamental freedoms by, people living with HIV/AIDS and members of vulnerable groups (paragraph 58).
- By 2003, develop strategies to combat stigma and social exclusion (paragraph 58).
- By 2003, develop a national legal and policy framework that protects in the workplace the rights and dignity of persons living with, and affected by, HIV/AIDS and those at greatest risk of HIV/AIDS (paragraph 69).

In the 2006 *Political Declaration*, Heads of State and Government, and representatives of States and Governments renewed their commitment to “intensifying efforts to enact, strengthen or enforce ... legislation ... and other measures to eliminate all forms of discrimination against, and to ensure the full enjoyment of all human rights and fundamental freedoms by, people living with HIV and members of vulnerable groups ... and developing strategies to combat stigma and social exclusion connected with the epidemic” (paragraph 29).

Specific actions in countries to follow up on these commitments and progress in meeting these targets have been extremely limited.

Nearly 40% of all countries globally, and almost half of those in sub-Saharan Africa, failed to meet their commitment to adopt, by 2003, legislation to prevent stigma and discrimination against people living with HIV. Moreover, few countries adopted legislation to protect vulnerable populations from discrimination.⁶¹ Since then, there have been some improvements, but many countries have still not enacted anti-discrimination legislation. Even where policies, laws and regulations are in place to promote and protect human rights, these have often not been rigorously enforced, often because of inadequate budget allocations for human rights monitoring.⁶² “Greater resources and political commitment must be mobilized to address problems of stigma, discrimination, gender and human rights”.⁶³

Parliamentarians should hold their governments to their commitments (for more details, see the section, Hold the executive to its promises, in Chapter 3) and secure policy and legal change to eliminate discrimination and provide privacy protections. Among other things, they can:

- strengthen legislation, regulations and other measures to eliminate all forms of discrimination against people living with HIV and members of key at-risk populations;
- review 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 cover HIV;
- recommend and oversee the training of relevant officials, including labour court judges and industrial tribunal magistrates who hear cases of employment-related discrimination.

BOX 26

What do the *International Guidelines on HIV/AIDS and Human Rights* say about what States should do to eliminate discrimination?

Guideline 5: States should enact or strengthen anti-discrimination and other protective laws that protect vulnerable groups, people living with HIV/AIDS and people with disabilities from discrimination in both the public and private sectors, that will 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 9: States should promote the wide and ongoing distribution of creative education, training and media programmes explicitly designed to change attitudes of discrimination and stigmatization associated with HIV/AIDS to understanding and acceptance.

Guideline 10: States should ensure that government and the private sector develop codes of conduct regarding HIV/AIDS issues that translate 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 HIV-related human rights, including those of people living with HIV, their families and communities.

Box 27

Examples of laws and policies on anti-discrimination, anti-vilification, privacy and partner notification, and the workplace

Anti-discrimination

The **Philippines** *AIDS Control and Prevention Act* of 1998 provides that, "... discrimination, in all its forms and subtleties, against individuals with HIV or persons perceived [as] or suspected of having HIV shall be considered inimical to individual and national interest ..." and establishes a number of specific prohibitions against discrimination in the workplace, in schools, in travel and habitation, in public service, in credit and insurance services, in hospitals and health institutions, and in burial services, and provides penalties for "all discriminatory acts and policies referred to in this Act".

In the **UK**, the *Disability Discrimination Act* (DDA) of 2005 extended discrimination protections for those living with HIV to the moment of diagnosis. Previously, protection from discrimination began only from the moment someone with HIV became unable to carry out day-to-day tasks. Under the Act, discrimination is prohibited in the workplace, education, housing, trade union membership, and the provision of goods and services, including the buying and selling of property.

Anti-vilification provisions

In **New South Wales, Australia**, the *Anti-Discrimination Act* makes it unlawful for a person "to incite hatred towards, serious contempt for, or severe ridicule of" anyone infected with HIV or thought to be HIV infected.⁶⁴

Privacy and partner notification

The **draft Indian HIV/AIDS Bill** contains particularly detailed and well-crafted provisions about privacy and disclosure of information. According to it, informed consent for disclosure of HIV-related information or private information is not required, except in those few cases where the disclosure is made:

1. by a health-care provider to another health-care provider who is involved in the provision of care, treatment or counselling of a person, when such disclosure is necessary to provide care or treatment in the best interest of that person; or
2. by an order of a court when it determines by such order that the disclosure of such information is necessary for the determination of issues and in the interest of justice in a matter before it; or
3. in suits or legal proceedings between persons, where the disclosure of such information is necessary in the initiation of such proceedings or for instructing counsel; or
4. in accordance with Section 13; or
5. if it relates to statistical or other information of a person that could not reasonably be expected to lead to the identification of that person; or
6. in accordance with Regulations made under the Act.

Section 13 deals with **partner notification**. A health-care provider may inform the partner of a person under their direct care of such person's HIV-positive status only when:

1. the health-care provider bona fide and reasonably believes that the partner is at significant risk of transmission of HIV from such person; and
2. the HIV-positive person has been counselled to inform such partner; and
3. the health-care provider is satisfied that the HIV-positive person will not inform such partner; and
4. the health-care provider has informed the HIV-positive person of the intention to disclose the HIV-positive status to such partner; and

5. such disclosure to the partner is made in person and with appropriate counselling or referrals for counselling.

In addition, the provision specifies that the “healthcare provider shall not inform a partner, particularly in the case of women, where there is a reasonable apprehension that such information may result in violence, abandonment or actions which may have a severe negative effect on the physical or mental health and safety of the HIV positive person, their children or someone who is close to them”.

Section 16 provides that, “no person shall print, publish, broadcast or in any manner release HIV-related information or private information of a person without the informed consent in writing of such person”.

In contrast, the partner notification provisions in the *Model Legislation on HIV/AIDS for West and Central Africa* are cause for serious concern. Parliamentarians in countries considering adopting the model law should ensure that these provisions are revised before the law is adopted. 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, or 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.

Workplace

In **Zimbabwe**, the *Labour Relations (HIV and AIDS) Regulations* prohibit mandatory HIV testing during recruitment and for employees. “No employer shall require, whether directly or indirectly, any person to undergo any form of testing for HIV as a precondition to the offer of employment ... It shall not be compulsory for any employee to undergo, directly or indirectly, any testing for HIV.” They also prohibit differential treatment in the workplace based on HIV status. “No employee shall be prejudiced in relation to (a) promotion; or (b) transfer; or (c) subject to any other law to the contrary, any training or other employee development programme; or (d) status; or in any other way be discriminated against on the grounds of his HIV status alone.” Finally, they provide that “No employer shall terminate the employment of an employee on the grounds of that employee’s HIV status alone”.

In **Malawi**, the *Malawi National HIV/AIDS Policy* guarantees all people freedom from discrimination on the grounds of HIV or AIDS status. Concerning the workplace, the policy prohibits employers from requiring any person to undergo testing for HIV as a precondition for employment.

The **Bahamas** protects persons living with HIV from workplace HIV testing under Section 6(c) of the *Employment Act of 2001*. “No employer or person acting on behalf of an employer shall discriminate against an employee or applicant for employment on the basis of ... HIV/AIDS ... by pre-screening for HIV status.” According to section 6(a), “No employer or person acting on behalf of an employer shall discriminate against an employee or applicant for employment on the basis of ... HIV/AIDS” by refusing to offer employment to an applicant for employment; or by dismissing or subjecting the employee to other detriment solely because of HIV; or by not affording the employee access to opportunities for promotion, training or other benefits.

For more details and additional examples, see:

(1) World Bank (2007). *Legal Aspects of HIV/AIDS, A Guide for Policy and Law Reform:*

siteresources.worldbank.org/INTHIVAIDS/Resources/375798-1103037153392/LegalAspectsOfHIVAIDS.pdf;

(2) The [Indian] HIV/AIDS Bill: www.lawyerscollective.org/%5Ehiv/Draft_Law_On_HIV.asp

Call for the development of a national plan to fight stigma and discrimination

Despite much rhetoric on stigma and discrimination, and despite the commitments they expressed in the *Declaration of Commitment* and in the *Political Declaration*, few countries have developed longer-term, strategic plans and specific programmes to address stigma and discrimination. Instead, countries often implement small, one-off projects, without a clear understanding of how to sustain action over a longer period and without clear priorities and cost estimates. Parliamentarians can take action in several key ways.

- Ensure that national AIDS authorities and their partners develop a prioritized, costed, and longer-term plan to fight stigma and discrimination, as part of, or complementary to, national AIDS plans. At a minimum, such a plan should contain:
 - multi-year social mobilization campaigns to protect and promote HIV-related rights and eliminate HIV-associated stigma and discrimination;
 - integration of HIV-related human rights and gender training into the curricula of health-care workers, social service providers, police, judges and prison officials;
 - review of existing anti-discrimination legislation and, if necessary, adoption of effective legislation;
 - ‘know your rights’ and legal and treatment literacy campaigns;
 - support for legal aid services for people living with, and most at risk of, HIV;
 - support for monitoring and enforcement mechanisms to guarantee HIV-related human rights.
- Take an active role in this process and ensure that people living with HIV and members of most-at-risk populations participate in all aspects of the development, implementation, monitoring and evaluation of the plan.

Advocate adequate funding for anti-stigma and anti-discrimination efforts

- Call upon your government and international donors to provide funding dedicated to the implementation of all components of the plan to fight stigma and discrimination, including adequate funding for legal services and for monitoring and enforcement mechanisms to guarantee HIV-related human rights.

Checklist 3

Components of anti-discrimination legislation

When drafting or reviewing legislation to safeguard persons living with HIV and people belonging to key at-risk populations from discrimination, the following issues should be considered.

- Does the legislation provide for protection against discrimination on the grounds of disability, widely defined to include AIDS?
- Does the legislation provide for protection against discrimination on the grounds of membership of a group made more vulnerable to HIV – for example, because of gender, sexual orientation, dependence on drugs?
- Does it prohibit discrimination against job applicants and workers on the basis of their real or perceived HIV status?
- Does the legislation contain the following substantive features:
 - ✓ coverage of direct and indirect discrimination;
 - ✓ coverage of those presumed to be infected, as well as caregivers, partners, family or associates;
 - ✓ coverage of vilification;
 - ✓ the justification for complaint only needs to be one of several reasons for the discriminatory act;
 - ✓ narrow exemptions and exceptions (e.g. superannuation and life insurance on the basis of reasonable actuarial data);
 - ✓ wide jurisdiction in the public and private sectors (e.g. health care, social security, welfare benefits, employment, education, sport, accommodation, clubs, trade unions, qualifying bodies, access to transport and other services)?
- Does the legislation provide for the following administrative features:
 - ✓ independence of a complaint body;
 - ✓ representative complaints (e.g. public interest organizations on behalf of individuals);
 - ✓ speedy redress (e.g. guaranteed processing of cases within a reasonable period, or fast-tracking of cases where the complainant is terminally ill);
 - ✓ access to free legal assistance;
 - ✓ investigatory powers to address systemic discrimination;
 - ✓ confidentiality protections (e.g. use of pseudonyms in reporting of cases)?
- Does the legislation provide for the institution administering the legislation (e.g. human rights commission or ombudsperson) to have the following functions: (1) education and promotion of human rights; (2) advising government on human rights issues; (3) monitoring compliance with domestic legislation and international treaties and norms; (4) investigating, conciliating, resolving or arbitrating individual complaints; (5) keeping statistics of cases and reporting on its activities?

Checklist 4

Components of privacy legislation

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

- Does the legislation provide for general privacy or confidentiality protection for medical and/or personal information, widely defined to include HIV-related data?
- Does the legislation prohibit unauthorized use and disclosure of such data?
- Does it provide for confidentiality of HIV-related personal information at the workplace?
- 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?
- Does the legislation provide for the independent agency administering the legislation (e.g. privacy or data-protection commissioner) to have the following functions: (1) education and promotion of privacy; (2) advising government on privacy issues; (3) monitoring compliance with domestic legislation and international treaties and norms; (4) investigating, conciliating, resolving or arbitrating individual complaints; (5) keeping data/statistics of cases and reporting on its activities?
- Does other general or public health legislation provide for the right of HIV-positive people to have their privacy and/or identity protected in legal proceedings (e.g. closed hearings and/or use of pseudonyms)?
- Does public health legislation provide for adequate privacy protections (e.g. use of coded rather than nominal data) where reporting cases of HIV or AIDS to public health authorities for epidemiological purposes?

Checklist 5

Components of employment law

When drafting or reviewing legislation to adequately cover the world of work, the following issues should be considered.

- Does it recognize HIV as a workplace issue, including the role of the workplace in responding to the epidemic?
- Does the legislation prohibit HIV testing for general employment purposes – i.e. appointment, promotion, training and benefits?
- Does the legislation prohibit mandatory testing in general and of specific employment groups (e.g. military, transport workers, hospitality/tourist industry workers, and sex workers)?
- Does the law provide for confidentiality of employees' medical and personal information, including HIV status?
- Does it provide that HIV infection is not a cause for termination of employment and that persons living with HIV should be able to work for as long as they are medically fit in available and appropriate employment? Does the law provide for employment security while HIV-positive workers are able to work (e.g. unfair dismissal rules) and social security and other benefits when workers are no longer able to work?
- Does it provide for reasonable accommodation – i.e. any modification or adjustment to a job or to the workplace that is reasonably practicable and will enable workers living with HIV to participate or advance in employment?
- Does it have a social dialogue mechanism to ensure successful implementation through cooperation and trust between employers, workers and their representatives and government and, where appropriate, with the active involvement of workers living with HIV?
- Does it include provisions that recognize the gender dimensions of HIV and the importance of equal gender relations and the empowerment of women to successfully reducing the prevalence of HIV?
- Does the legislation require implementation of universal precautions and infection control measures, including training and provision of equipment in all settings involving exposure to blood or body fluids?
- Does the legislation require provision of access to information and education about HIV for occupational health and safety reasons (e.g. workers travelling to areas of high incidence)?
- Does workers' compensation legislation recognize occupational transmission of HIV?
- Does the law provide for access to post-exposure prophylaxis (PEP) for occupational transmission of HIV and non-occupational transmission among all workers and persons of working age?

CHAPTER 7

Prevention

Summary

Why leadership and action on HIV prevention are so important

- Increasing access to HIV prevention is an urgent priority. The number of new HIV infections continues to climb, posing a major threat to the capacity of countries to respond.
- Strong evidence of effectiveness exists for a broad array of HIV prevention strategies, but most people at risk of HIV infection have little or no access to basic prevention tools. All too often, national governments are unwilling to provide access to all necessary tools – although they committed to coming as close as possible to universal access to prevention by 2010.

What you can do

- Parliamentarians can do much to help achieve universal access to prevention by, among other things: (1) calling for comprehensive, evidence-informed prevention programmes that prioritize the HIV prevention needs of key affected groups and populations, and actively participating in setting national prevention priorities; (2) rejecting coercive approaches to HIV prevention that are ineffective; (3) calling on national governments and international donors to close the HIV prevention resource gap; (4) calling upon donors to remove any funding restrictions that limit access to scientifically proven or informed HIV prevention strategies; (5) reforming legal frameworks to eliminate barriers to prevention; and (6) advocating new prevention strategies.

Why are leadership and action on HIV prevention so important?

Increasing access to HIV prevention: an urgent priority

The number of new HIV infections continues to climb, with an estimated 2.5 million people having been newly infected with HIV in 2007. Globally, the total number of people living with HIV also continues to grow. Left unchecked, the epidemic will have an ever-increasing impact on individuals, communities and nations.

We should be winning in HIV prevention ...

Strong evidence of effectiveness exists for a broad array of HIV prevention strategies;⁶⁵ political commitment on HIV has become stronger in many countries; and financing for HIV programmes in low- and middle-income countries is increasing rapidly. However, the effort to reduce the number of new HIV infections is faltering.

For every patient who began antiretroviral therapy (ART) in 2006, six other individuals became infected with HIV.⁶⁶ If current trends continue,

it is projected that 60 million more HIV infections will occur by 2015. Unless the number of new infections is sharply reduced, global efforts to make HIV treatment widely available will become increasingly difficult, and millions more people may die as a result of preventable HIV infections.

By delivering comprehensive HIV prevention to those who need it, half of all infections projected to occur between now and 2015 could be averted.⁶⁷

... but most people at risk have little or no access to prevention

Despite the numerous prevention services and commodities currently available, most people at risk of HIV infection have little or no access to them. Coverage levels for essential prevention strategies remain woefully inadequate.⁶⁸

- **Condoms.** Only 9% of risky sexual acts worldwide are undertaken while using a condom, and the global supply of condoms is millions short of what is needed.
- **HIV counselling and testing.** In the most heavily affected countries of sub-Saharan Africa, only 12% of men and 10% of women know their HIV status.
- **Treatment for sexually transmitted infections.** Fewer than 20% of people with a sexually transmitted infection (STI) are able to obtain treatment, even though untreated STIs greatly increase the risk of HIV infection.
- **Prevention of mother-to-child transmission.** Years after clinical trials demonstrated that a brief, inexpensive antiretroviral regimen could reduce the risk of mother-to-child HIV transmission by 50%,⁶⁹ only a small minority of HIV-infected pregnant women in low- and middle-income countries receive antiretroviral prophylaxis.
- **Prevention for key at-risk populations.** Prevention services reach only 9% of men who have sex with men, 8% of people who inject drugs, and less than 20% of sex workers.
- **Prevention in health-care settings.** An estimated 1.5 million tests that should have been performed on donated blood in 2004 failed to be carried out, and 40% of injections administered in health-care settings were unsafe.

HIV and AIDS is about sexuality, gender, drug use, violence, men who have sex with men, sexual orientation, trafficking in human beings and many other matters. It is about the full respect for human rights. To move forward on HIV prevention, we must be prepared and dare to address all these matters, with open eyes and open minds, realizing that the fight against HIV will never be won through easy slogans and acronyms.

– Lennarth Hjelmaker, Special Ambassador on HIV/AIDS, Sweden

There are many barriers to scaling up HIV prevention, but they can be overcome

HIV prevention can be controversial and uncomfortable for individuals, societies and governments to confront. It forces discussion of difficult issues such as sex, sexuality and drug use. There can be an unwillingness to provide access to the full range of options that are known to be successful in HIV prevention. In many places, there is cultural resistance to addressing the needs of vulnerable populations and a reluctance to recognize and act on societal and structural factors that fuel the epidemic.

Many countries also have legal restrictions, which, coupled with stigma and discrimination, can drive vulnerable populations underground and thereby make HIV prevention efforts inaccessible to them. Stigma and discrimination also discourage the kind of political leadership required to implement a robust and evidence-informed HIV prevention effort.

In addition, other factors have slowed global efforts to bring HIV prevention to scale.

- **Inadequate financing:** While financing for HIV has increased dramatically in recent years, available funding is only slightly more than half of what is needed to support a comprehensive, scaled-up response⁷⁰ (see Chapter 4 for more details).
- **Misallocation of resources:** Many countries do not direct their limited funds where they would have the greatest impact. Misallocation of resources sometimes occurs as a result of non-scientific restrictions on how HIV prevention assistance may be used or because of donors' conditions.⁷¹
- **Service fragmentation:** HIV prevention has frequently not been integrated into schools, workplaces and other institutions, and prevention efforts are insufficiently linked with other health-related service systems, such as TB or sexual and reproductive health.

In addition, there are barriers to the development of new health technologies, such as vaccines and microbicides, including limited global spending on AIDS vaccine and prevention technology development, and limited scientific capacity in low- and middle-income countries.

Experience teaches, however, that such impediments can be overcome. Numerous countries have demonstrated the feasibility of implementing comprehensive HIV prevention efforts. Prevention efforts in countries that have been successful in preventing a major epidemic from emerging (e.g. Senegal) or reversing their epidemic (e.g. Brazil) share a number of characteristics – adequate and sustained financing, political support, evidence-informed action, use of mass media and other channels to raise HIV

awareness, promotion of condoms and control of STIs, anti-stigma measures, and involvement of affected communities.⁷²

In recent years, countries throughout the world have experienced success in expanding access to HIV prevention. Examples include the following.⁷³

- **Cambodia:** National HIV prevalence was cut in half following implementation of comprehensive HIV prevention for sex workers and their clients.
- **Haiti:** Although it is the poorest country in the Western Hemisphere, Haiti has achieved HIV prevention coverage well above global averages, almost halving HIV infection levels among pregnant women between 1998 and 2004.
- **India:** The Avahan India AIDS Initiative established sex-worker programmes in 76 districts and 550 towns, distributing 5.6 million condoms each month and increasing the percentage of sex workers who visit a sexually transmitted disease (STD) clinic from 26% to 90% in little over a year.
- **Iran:** Iran has dramatically expanded access to HIV prevention, treatment and care services for people who use drugs. At the end of 2006, HIV clinics were operating in one-third of all prisons in Iran, and methadone substitution therapy was reaching 55% of all prisoners in need.

BOX 28

Key resources: HIV prevention

Intensifying HIV Prevention – UNAIDS Policy Position Paper (2005)

This paper defines the central actions that must be taken to arrest the spread of HIV. The paper is directed towards all those who have a leadership role in HIV prevention, treatment and care, including parliamentarians.

Practical Guidelines for Intensifying HIV Prevention: Towards Universal Access (2007)

These practical guidelines are designed to help policy-makers and planners tailor their national HIV prevention response so that they respond to the epidemic dynamics and social context of the country and populations who are most vulnerable to, and at risk of, HIV infection.

Bringing HIV Prevention to Scale: An Urgent Global Priority (2007)

The challenge of delivering HIV prevention services to those who need them is the focus of this report by the Global HIV Prevention Working Group. It contains a series of recommendations aimed at bringing “the promise of HIV prevention to the countries and communities that need it the most”.

The full text of the UNAIDS policy position paper and practical prevention guidelines can be accessed via www.unaids.org.

Bringing HIV Prevention to Scale and other publications by the Global HIV Prevention Working Group are available at www.GlobalHIVPrevention.org.

What parliamentarians can do to help achieve universal access to prevention

Provide strong, informed and committed leadership on prevention

- **Use every opportunity to speak out openly about the need to take effective action to prevent the spread of HIV**, recognizing that governments have often shied away from undertaking comprehensive HIV prevention because of competing economic and political priorities and the association of HIV with issues such as sex, sex work, sex between men, and drug use. **There is no doubt that these can be difficult and sensitive issues, but they must be addressed transparently, informed by evidence, if an effective response to HIV prevention is to be mounted.**
- **Promote programmes that prioritize the HIV prevention needs of key affected groups and populations.** This is not only the right thing to do in terms of protecting the human rights of all members of society, it is also the best way to prevent HIV.
- **Reject coercive approaches to HIV prevention**, acknowledging that they are ineffective. Such approaches include mandatory HIV testing, restriction of movement and criminalization of harm reduction measures and HIV prevention modalities. These tend to drive individuals away from health information and services, have an adverse effect on prevention goals, and violate human rights. Effective HIV prevention measures are those that emphasize human dignity, responsibility and empowerment through access to health information, services and community support and participation.⁷⁴
- **Advocate the inclusion of people living with or vulnerable to HIV as vital partners in HIV prevention efforts.** Do not characterize any group as “vectors of the disease”, do not single out populations for blame and persecution and do not marginalize or stigmatize them.

Advocate new prevention technologies

Advocate new prevention technologies such as HIV preventive vaccines and microbicides. In particular, ask for:

- increased global spending on development of vaccines and microbicides;
- greater investment in scientific teams and clinical trials site infrastructure in low- and middle-income countries;
- strengthening of ethical and regulatory agencies;
- development of a national vaccine and microbicide plan to build a favourable environment for vaccines and microbicides.

BOX 29

What about male circumcision?

A new and promising tool has been added to the roster of efficacious HIV prevention strategies. Efficacy studies in Kenya, South Africa, and Uganda indicate that male circumcision reduces the risk of female-to-male sexual HIV transmission by roughly 60%.⁷⁵

These results are highly significant, but it is essential to underline that male circumcision *does not provide complete protection against HIV*. Furthermore, HIV-infected circumcized men can still transmit HIV to sexual partners. Thus, there is no strong evidence that male circumcision reduces the risk of HIV transmission to a female partner and there is no evidence that male circumcision reduces the risk of HIV transmission during anal sex to the receptive partner, whether male or female. Because the protective effect of male circumcision is only partial, male circumcision must be promoted *in combination* with other methods to reduce the risk of sexual transmission of HIV.

Promotion of adult male circumcision in HIV-negative men is one component of a comprehensive approach to HIV prevention. "A human rights-based approach to the development or expansion of male circumcision services requires measures that ensure that the procedure can be carried out safely, under conditions of informed consent, and without coercion or discrimination".⁷⁶

In order to best protect men and their sexual partners in the context of male circumcision, States that introduce or expand male circumcision services should develop costed national plans and allocate resources for male circumcision services *without taking away resources from other essential health programmes*,⁷⁷ and ensure that:

- accurate information about the *partial* protective effect for men of male circumcision, as well as the risks and benefits associated with the procedure, is accessible for all the population – men, women and adolescents;
- the gender implications of male circumcision as an HIV prevention method are addressed (this includes an obligation to monitor and minimize potential harmful outcomes of promoting male circumcision as an HIV prevention method such as unsafe sex, sexual violence, or conflation of male circumcision with female genital mutilation);
- male circumcision services are accessible to *all the male population*, starting in areas with high HIV prevalence and progressively expanding outwards;
- *non-discrimination in access* to male circumcision services is ensured;
- male circumcision is *integrated into comprehensive HIV prevention programming*;
- services are *safe*;
- there is a *legal, regulatory and policy framework* to ensure all of the above.

For more details, see: (1) WHO/UNAIDS (2007). *New Data on Male Circumcision and HIV Prevention: Policy and Programme Implications*. (2) UNAIDS (2007). *Safe, Voluntary, Informed Male Circumcision and Comprehensive HIV Prevention Programming. Guidance for decision-makers on human rights, ethical & legal considerations*. Both papers can be accessed via www.unaids.org.

Actively participate in setting and supporting national prevention priorities

- ❑ **Ensure that national authorities and their partners take stock of where, among whom and why new HIV infections are occurring.** Understanding this enables countries to review, plan, match and prioritize their national responses to meet these needs.
- ❑ **Ensure that national authorities and their partners, based on a thorough and up-to-date understanding of the national epidemic, develop, monitor and update a national strategic HIV plan that simultaneously brings evidence-informed HIV prevention and treatment to scale and acts on the drivers of the epidemic, including harmful social norms and laws, gender inequality and neglect of human rights.**
- ❑ **Take an active role in this process and ensure that civil society, including people living with HIV and members of key populations at higher risk, can meaningfully participate** in all aspects of the development, implementation and evaluation of the plan.
- ❑ Advocate the establishment of ambitious HIV prevention coverage and outcome targets aiming at universal access, as well as the establishment of interim targets that ensure the establishment of programmes to overcome obstacles to universal access in the form of harmful gender norms, HIV-related discrimination, and discrimination and marginalization of vulnerable groups. Data should be collected for all populations at risk and disaggregated by sex, age and marital status.
- ❑ Advocate regular reviews of the plan, for revisions, updates and refinement, where required, and take an active role in these reviews.

Box 30 Know your epidemic

WHO and UNAIDS define different types of HIV epidemics.

Hyperendemic scenarios: HIV prevalence exceeds 15% in the adult population, due to extensive heterosexual multiple concurrent partner relations with low or inconsistent condom use.

Generalized HIV epidemics: HIV prevalence is consistently over 1% in pregnant women. HIV is firmly established in the general population. Although subpopulations at high risk may contribute disproportionately to the spread of HIV, sexual networking in the general population is sufficient to sustain an epidemic independent of subpopulations at higher risk of infection.

Concentrated HIV epidemics: HIV prevalence is consistently over 5% in at least one defined subpopulation but is below 1% in pregnant women in urban areas. HIV has spread rapidly in one or more defined subpopulations, but is not well-established in the general population. The future course of the epidemic is determined by the

frequency and nature of links between the subpopulations with high rates of HIV and the general population.

Low-level HIV epidemics: HIV prevalence has not consistently exceeded 5% in any defined subpopulation. HIV has never spread to significant levels in any subpopulation. Recorded infection is largely confined to individuals with higher risk behaviour – e.g. sex workers, people who inject drugs, and men who have sex with men.⁷⁸

Review and reform legal frameworks to eliminate barriers to prevention

- Review and, if necessary, reform legal frameworks to ensure that people's ability to control their risk of infection through comprehensive programmes is protected. This includes the following measures.
 - The elimination of gender-based inequalities that fuel the epidemic (for more details, see Chapter 9).
 - Access to health care and other services free from discrimination (see Chapter 6);
 - Removal of barriers to HIV prevention programmes, particularly laws or regulations that impede (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, men who have sex with men, people who use drugs and prisoners (see Chapter 12); and (d) access to education.
 - Review and reform of criminal laws (see Chapter 13) and correctional systems (see Chapter 12), to ensure that they do not result in ineffectual or harmful attempts to control HIV and that they respect the rights of all people, including people living with HIV and key populations at higher risk.

Box 31

What do the *International Guidelines on HIV/AIDS and Human Rights* say about HIV prevention?

Guideline 6 (as 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 [and] adequate HIV prevention ... information ...

States should also take measures necessary to ensure for all persons, on a sustained and equal basis, the availability and accessibility of quality goods, services and information for HIV/AIDS prevention ... including diagnostics and related technologies for preventive ... care of HIV and related opportunistic infections and conditions.

Hold your government to its promises

Governments, through the 2005 World Summit Outcome, the Gleneagles Communiqué of the Group of Eight (G8) and the 2006 *Political Declaration*, have established the **goal of getting as close as possible to universal access to HIV prevention, treatment, care and support by 2010.**

Specifically, in the *Political Declaration*, Heads of State and Government, and representatives of States and Governments committed themselves to “**intensifying**” **prevention efforts** and to “**overcoming legal, regulatory or other barriers** that block access to effective HIV prevention ...” (paragraph 22); and to “finding ... solutions to overcome barriers in pricing, tariffs and trade agreements, and to making improvements to legislation, regulatory policy, procurement and supply chain management in order to accelerate and intensify access to affordable and quality HIV/AIDS prevention products ...” (paragraph 42).

These commitments build on the *Declaration of Commitment* (2001), in which countries committed themselves to several time-bound prevention targets:

- **By 2003**, establish time-bound national targets to ... reduce **by 2005** HIV prevalence among young men and women aged 15 to 24 in the most affected countries by 25% and by 25% globally by 2010, and intensify efforts to ... challenge gender stereotypes and attitudes, and gender inequalities in relation to HIV/AIDS ... (paragraph 47);
- **By 2003**, establish national prevention targets ... to reduce HIV incidence for those identifiable groups ... which currently have high or increasing rates of HIV infection, or which ... are at highest risk of new infection (paragraph 48);
- **By 2005**, strengthen the response to HIV/AIDS in the world of work by establishing and implementing prevention and care programmes in public, private and informal work sectors, and take measures to provide a supportive workplace environment for people living with HIV/AIDS (paragraph 49);
- **By 2005**, develop and begin to implement ... strategies that facilitate access to HIV/AIDS prevention programmes for migrants and mobile workers ... (paragraph 50);
- **By 2005**, ensure: that a wide range of prevention programmes ... is available in all countries ... including information, education and communication ...; expanded access to essential commodities, including male and female condoms and sterile injecting equipment; harm-reduction efforts related to drug use; expanded access to voluntary and confidential counselling and testing; safe blood supplies; and early and effective treatment of sexually transmittable infections (paragraph 52).

Advocate greater and equitable HIV prevention spending

- In the context of advocacy for greater spending on AIDS (see Chapter 4), **call on your national government and on international donors to close the HIV prevention resource gap.**
- **Call upon donors to remove any funding restrictions** that limit access to scientifically proven or evidence-informed HIV prevention strategies.
- **Advocate equity** in the amount of resources and programming serving the needs and rights of groups most affected by HIV.
- **Advocate the combination of measures to reduce the behaviours that put people at immediate risk of HIV infection** – such as unprotected sex and using non-sterile injecting equipment – **with appropriate measures and efforts to define and mitigate the drivers of the epidemic.** Mitigating the drivers of the epidemic requires action that addresses gender inequality and ensures that the human rights of all people are respected. Failure to invest in measures that mitigate the drivers of the epidemic can undermine the use of prevention services and result in lost opportunities to prevent new HIV infections.

Checklist 6

The principles of effective HIV prevention⁷⁹

Crucial to the success of any effective HIV prevention effort are a number of overarching principles in which prevention programmes should be grounded. Check here whether your country's prevention efforts are based on these principles.

- All HIV prevention efforts/programmes must respect **human rights, including gender equality.**
- HIV prevention programmes must be **differentiated and locally adapted** to the relevant epidemiological, economic, social and cultural contexts in which they are implemented.
- HIV prevention actions must be **evidence-informed**, based on what is known to be effective, and investment to expand the evidence base should be strengthened.
- HIV prevention programmes must be **comprehensive** in scope, using the full range of policy and programmatic interventions known to be effective.
- HIV prevention is for life: therefore, both delivery of existing interventions and research and development of new technologies require a **long-term and sustained effort.**
- HIV prevention programming must be undertaken with sufficient **coverage, scale and intensity** to make a significant impact.
- **Community participation** of the intended beneficiaries of the prevention programmes is critical to the programmes' success.

Checklist 7

The components of comprehensive HIV prevention

In assembling a national HIV prevention plan, each country should prioritize and refer to the following roster of evidence-informed HIV prevention approaches.⁸⁰

Preventing sexual transmission

- Behaviour-change programmes (to shift behaviour towards safer-sex practices, delay initiation of sexual activity in young people, and reduce the number of partners)
- Condom promotion
- HIV counselling and testing
- Diagnosis and treatment of STIs
- Adult male circumcision

Preventing blood-borne transmission

- Provision of clean injecting equipment and other materials to reduce harms associated with unsafe drug use (including by inhalation) to people who use drugs
- Methadone or other substitution therapy for drug dependence
- Provision of blood transfusion service to ensure blood safety (including routine screening of all donated blood)
- Infection control in health-care settings (including injection safety, universal precautions, and antiretroviral prophylaxis following potential HIV exposure)

Preventing mother-to-child transmission

- Primary HIV prevention for women of childbearing age
- Antiretroviral drugs
- Prevention of unintended pregnancy in HIV-positive women
- Prevention of transmission through breastfeeding
- Safe and hygienic caesarean delivery (in the case of high maternal viral load)

Social strategies and supportive policies

- HIV-awareness campaigns (including mass media)
- Anti-stigma measures
- Gender equity and women's empowerment initiatives
- Poverty-elimination initiatives
- Initiatives to achieve universal primary education
- Involvement of communities and HIV-infected individuals
- Visible political leadership
- Engagement of a broad range of sectors in HIV awareness and prevention measures
- Legal reform to create an environment supportive of HIV prevention

New prevention technologies

- In addition, countries should develop plans detailing their contribution to vaccine and microbicide development and research, and preparing for their eventual availability.

CHAPTER 8

Treatment, care and support

Summary

Why leadership and action on HIV treatment, care and support are so important

- AIDS killed some 2.1 million people in 2007. If everyone had access to treatment (including antiretroviral therapy – ART), care and support, the death toll would be much lower.
- Treatment for AIDS has been shown to be safe, effective and feasible in even the poorest parts of the world. Political momentum is building and governments are beginning to show their willingness to help alleviate the suffering caused by the epidemic. Definite targets have been set that are both ambitious and attainable. Nevertheless, progress so far has been disappointingly slow, and the current rate of treatment scale-up is not nearly sufficient to achieve the target of universal access by 2010. Governments must now demonstrate real commitment if they are to keep their promises. Millions of lives are at stake.

What you can do

- Parliamentarians can do many things to help achieve universal access. Among them are: (1) advocating comprehensive treatment, care and support, and greater domestic and international funding for universal access; (2) ensuring that countries devote a greater proportion of national budgets to health and health system strengthening, and that donors support these efforts; (3) removing trade barriers blocking access to medicines and reforming other laws that create barriers to universal access to treatment; (4) supporting patent pools for essential medicines.

Why are leadership and action on HIV treatment, care and support so important?⁸¹

Every day, the number of people needing treatment, care and support increases

An estimated 33.2 million people worldwide were living with HIV at the end of 2007 – and every day the numbers of progressively sick people increase. They need treatment, care and support to cope with the traumatic health, emotional and social impact on themselves, their families and other loved ones.

Treatment delivery must expand much more rapidly

There are encouraging global trends in the scale-up of ART. In 2006, almost 700 000 people received treatment for the first time. By December 2006, it was estimated that 2 million people living with HIV were receiving treatment in low- and middle-income countries, representing 28% of the estimated 7.1 million people in need.⁸²

[A]ccess to medication in the context of pandemics, such as HIV/AIDS, is one of the fundamental elements to achieve progressively the full realization of the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.

– Political Declaration on HIV/AIDS, paragraph 12

However, most people with HIV in low- and middle-income countries continue to lack access to life-saving HIV medicines, including antiretrovirals – and often even to basic medical care. The pace of treatment delivery must accelerate more rapidly. Otherwise, the world will fall short of even the most modest interpretation of the target of coming “as close as possible” to universal access to treatment, care and support by 2010,ⁱ with 5 million people in need still not having access.⁸³ Much greater efforts are required to achieve the targets agreed by governments.

Box 32

A best practice example: Scaling up access to treatment in Brazil⁸⁴

In Brazil, health care was declared a right in the Federal Constitution of 1988. In 1996, a federal law granted free ART to all HIV-positive patients with a medical indication for treatment. The Brazilian AIDS Programme established clinical centres, a laboratory infrastructure providing free viral load and CD4 counts, condom distribution and outreach programmes. In the first year, ART was received by 2000 people and, by 2004, there were 140 000 on ART. A large number of drugs are available, many of which are locally produced by public laboratories. It is estimated that the total expenditure on ART from 1996 to 2002 was approximately US\$ 2 billion. There was some criticism that this was excessive but it has been estimated that, besides the social gains (better quality of life and reduced morbidity and mortality), a net saving of approximately US\$ 200 million during this period was attributable to the implementation of the HIV care policy. AIDS-related deaths fell by approximately 90 000, some 60 000 new AIDS cases were prevented, and more than 600 000 hospital admissions were avoided.

Treatment access must be equitable

In addition, treatment must reach marginalized groups, children, and people in rural areas, who have not benefited enough from treatment scale-up efforts.⁸⁵

WHO and UNAIDS recommend the following measures to promote equity in the distribution of HIV treatment and care in resource-limited settings.

ⁱ According to the most common definition, universal access to treatment is achieved when 80% of all people in urgent need of treatment are receiving it. It has been estimated that, under this definition, universal access means at least 10 million people must be receiving treatment by the end of 2010. At the end of 2006, 7.1 million were in need of treatment. But this number will continue to grow because people who started treatment in previous years must continue to receive medication, and each year many hundreds of thousands of people progress to the stage of disease at which treatment is required.

1. Mobilize, without delay, a wide range of partners to scale up HIV treatment and care. Scale-up is not only an urgent public health and development priority but also an ethical and human rights imperative within the framework of a comprehensive response to AIDS.
2. Establish a broadly representative ethics advisory body (including people living with HIV), linked to the national AIDS programme or council, to plan, promote and monitor equity in the scale-up and distribution of HIV treatment and care services.
3. Create opportunities for public dialogue on equitable access to HIV treatment and care.
4. Develop policies for scaling up HIV treatment that are firmly based in human rights and ethical principles.
5. Identify vulnerable, marginalized or other potentially underserved populations. Depending upon the local context, these groups may include women, children, the poor, rural populations, sex workers, people who inject drugs, men who have sex with men, refugees and migrants.
6. Consider the need for special policies and outreach programmes to prioritize these groups and to overcome barriers to their accessing care.
7. The ethics body should help to ensure that a fair process is established for setting priorities in the distribution of HIV treatment.
8. Define or adopt measurable indicators to monitor the fairness of HIV treatment scale-up at the national and community level.
9. Responsible officials, including the ethics advisory body, should use monitoring and evaluation data to ensure that HIV programmes are producing equitable results.⁸⁶

Access to treatment is a human right

People living with HIV have fundamental rights to health and life. These should be respected, protected and fulfilled. Treatment with ART and other medications is essential to provide additional years of healthy life to people living with HIV and to make HIV a manageable, chronic disease. Although the data are still relatively limited, there is evidence that, overall, the response to treatment in both adults and children in resource-limited countries can be as good as in high-income settings.⁸⁷ This success requires strong and continuing support to patients in adhering to their ART regimens so they avoid breaks in their treatment that could cause failure of, and/or resistance to, the antiretroviral drugs being used.

Families, communities and nations benefit when people living with HIV are provided with treatment, care and support

In addition to the obvious benefits to individuals living with HIV, families, communities and nations also benefit in many ways when people living with HIV are enabled to live longer and fuller lives. When parents' lives are prolonged, children are responsibly cared for longer. Losses to household and national income are postponed. The blows to overall development prospects from the premature deaths of so many productive adults are delayed, allowing coping mechanisms to be put in place.

Where they have been guaranteed care and support (including protection from discrimination and other abuses), people living with HIV have been leaders in combating the disease. They have helped break the silence about HIV and given the issue a real, human face. They have fought both inaction and abuses. They have mobilized their communities, the media and government. With their personal knowledge of the issue, they have encouraged sound policies and responses on the challenges posed by HIV.

Box 33

Is antiretroviral treatment (ART) necessary?⁸⁸

Yes. A few years after infection with HIV, the virus weakens the patient's immune system to the point that opportunistic infections can start to take hold. These opportunistic infections – such as TB and pneumonia – can kill without treatment. Medicines to treat most opportunistic infections are available (though they are often too expensive for the majority of patients). But treating opportunistic infections is only a temporary solution, since HIV continues to attack the immune system. After one infection is cured, others inevitably follow. ART is needed in order to greatly reduce the amount of the virus (viral load) in the body. It does not eliminate the virus completely and is, therefore, not a complete cure, but it can improve a patient's quality of life and prolong survival for many years when taken consistently. Over the last few years, the introduction of ART in Europe and the US has cut AIDS deaths by over 70%. In Brazil, the use of ART cut AIDS mortality by 51% between 1996 and 1999. Treatment is also a powerful incentive to get tested.

Prevention, treatment, care and support are a continuum

Providing treatment, care and support for people living with HIV is not just morally the right thing to do, it is also essential for successful prevention. Worldwide experience shows that HIV epidemics cannot be defeated where treatment, care and support are lacking. Prevention efforts can only succeed when people do not fear losing their jobs, families, friends and social standing because they have HIV or are perceived to be at high risk, and when they can access confidential, voluntary counselling and testing and medical care, such as ART, without fear.

Despite challenges, countries can achieve universal access

Many challenges must be overcome on the road towards universal access.⁸⁹

Financing universal access

Meeting the commitment to achieve universal access by 2010 hinges upon it being fully financed. Sufficient resources must be made available to fund each nationally agreed AIDS strategy in full, as promised by all UN Member States in June 2006.⁹⁰

Strengthening health systems

Well-functioning public health systems are essential. Health systems in low- and middle-income countries have been severely under-funded for decades. Few governments in low- and middle-income countries commit a substantial proportion of their budget to their health system, in order to deliver a basic package of services. Only two Member States of the African Union have fulfilled their commitment to devote 15% of national budgets to health.⁹¹ In addition to increased domestic spending, the WHO Commission on Macroeconomics and Health estimated that an additional US\$ 27 billion per annum in aid is needed to strengthen the capacity of health systems in low-income countries so that they can deliver basic health-care packages effectively. Meeting this target would require a five-fold increase in donor spending on health and does not include free access to HIV treatment for everyone in need.⁹²

Addressing the health-worker shortage

Addressing the health-worker shortage is an essential component of efforts to strengthen health systems. In many countries hard-hit by AIDS, there is a crisis due to the lack of skilled health workers in the face of enormous demand for public health services. Factors that push health workers to leave public sector jobs to migrate or work in the private sector include low pay, poor occupational health and safety, lack of training and prospects of career advancement, poorly supplied medical facilities, too few staff, and poor management and overall health system governance. The health-worker shortage is particularly complex in countries most affected by HIV. WHO and UNAIDS are advising low- and middle-income countries to strengthen and expand the existing workforce to deliver HIV-related services through a number of measures, including the use of 'task-shifting'. This involves shifting tasks from more- to less-specialized health workers (e.g. from specialists to physicians, physicians to nurses, and nurses to community health workers and lay providers, including people living with HIV). Parliamentarians in concerned countries should familiarize themselves with current best practices, efforts to standardize training and certification criteria, and necessary reforms of any legal and regulatory frameworks, while ensuring that the necessary resources are available for costing and implementation of task-shifting, where appropriate.

Making medicines affordable

Ensuring that medicines are affordable for all is critical to achieving universal access to treatment. Affordable pharmaceuticals are needed to increase access, and also to maximize and sustain the impact of funding for HIV. A number of mechanisms are available to help make HIV medicines more affordable. These include generic competition, local production, differential pricing by research-based and generic pharmaceutical companies, voluntary licensing by innovator to generic companies, high-volume and bulk-purchasing arrangements, elimination of tariffs and taxes on essential medicines, and the use of flexibilities in the international trade and intellectual property rules (through the TRIPS Agreement and other WTO mechanisms) to achieve wider access to affordable generic medicines.

Generic competition, along with differential pricing, particularly for low-income countries, has reduced the price of first-line ART from US\$ 10 000 per patient per year in 2000 to as low as US\$ 130 in many low-income countries. Over 50% of patients on ART in low- and middle-income countries rely on generic medicines from India. However, with pharmaceutical-producing countries such as India having reformed their patent laws to comply with the expanded patent protection required under the TRIPS Agreement, the production of more affordable generic versions of newly developed and patented second- and third-generation HIV medicines will become more difficult. Newer antiretroviral therapies may be safer and more effective, or needed as second-line treatment for patients developing side effects or resistance. Yet estimates indicate that switching just 10% of patients in Africa to newer, second-line treatments would double their national drugs bills.⁹³

These are serious challenges, but none of these problems is insolvable and parliamentarians have an important role to play in overcoming them.

Box 34

An example of leadership and action on access to treatment, care and support

Over 30 parliamentarians from the African Great Lakes region, as well as members of parliament from Germany, Poland and the United Kingdom and experts from civil society and international organizations met at the **Regional Seminar on HIV/AIDS Prevention, Treatment, Care and Support** on 18–19 April 2007 in Nairobi, Kenya, to review parliamentary performance in monitoring government in the realization of the Abuja Call – namely the promise of African governments to allocate 15% of the annual budget to health care. Many of the presentations focused on the role of parliamentarians in moving towards universal access. More information and copies of the presentations can be obtained via www.awepa.org.

What parliamentarians can do to help achieve universal access to treatment, care and support

Advocate treatment, care, support and protection

- **Explain** to other leaders – at international, regional, national and local levels – **the many reasons why providing treatment, care and support is essential.**
- **Advocate all the elements that are needed to provide meaningful treatment, care and support:** voluntary and confidential counselling and HIV testing (see Chapter 5); affordable and accessible essential medicines and supplies; improved laboratory infrastructure to monitor patients enrolled in care and treatment programmes; quality medical treatment, including ART; prevention of parent-to-child transmission (see Chapter 10); economic and social support to families and caregivers; support for improving home- and community-based care; and legal and policy steps to prevent, challenge and redress any form of discrimination or abuse in health and social system settings, schools and government offices (see Chapter 6).
- **Advocate the integration of prevention and treatment services,** explaining that only a comprehensive and coordinated effort will overcome the most difficult challenges in ending the epidemic. False separation of prevention and treatment, divisive ‘either–or’ debates, and competition over resources must end.
- In every forum, **emphasize the fact that people living with HIV and members of key populations at higher risk have the same human rights and responsibilities as all other citizens,** including protection against discrimination in any form. Explain that prejudice and fear drive people with HIV to avoid counselling, testing or care, which perpetuates the epidemic.
- **Press for a clear, substantial role for associations of people living with HIV, in all efforts pertaining to HIV,** whether in policy-making, delivery of services, public rallies or the response from the private sector. Work with networks of people living with HIV and **support treatment and prevention literacy programmes.** The treatment and prevention literacy of HIV-positive people is one of the most important ways to ensure appropriate access and adherence to treatment. It is also a fundamental component of ‘positive prevention’ programmes. These programmes help people living with HIV to protect their sexual health, to avoid new STIs, to delay HIV disease progression, and to avoid passing their infection on to others. Meet with representatives of networks and find out what support they need in order to initiate or expand treatment literacy and adherence-support programmes, as well as ‘positive prevention’ programmes.

- **Promote access to treatment for children** (see Chapter 10) **and for communities that are marginalized or excluded** (see Chapter 12). Support programmes that help connect HIV-positive sex workers, men who have sex with men, people who use drugs, prisoners, migrants, refugees, the poor and ethnic minorities to treatment, care and support, regardless of their legal status.
- **Advocate measures, including elimination of patient out-of-pocket fees, to ensure that inability to pay is not a barrier to treatment and care; advocate ancillary services, in addition to treatment, to be provided free of charge so that poor people are able to begin and sustain treatment.** What is called ‘free treatment’ often involves hidden costs for the vast majority of people. Transportation costs and charges for diagnostic tests and medical care still put life-saving treatment out of reach for many.
- **Promote access to ongoing ART for women who have participated in prevention of mother-to-child transmission (PMTCT) programmes.** There are many reasons to prioritize treatment for women, including pregnant women and mothers: to provide treatment to them in their own right, to prevent mother-to-child transmission, to prevent the dissolution of families and to prevent the orphaning of children. It is an ethical imperative that women participating in PMTCT programmes are able to access ongoing ART for themselves. Support groups of women, human rights advocates and networks of HIV-positive women in their efforts to bring this issue to the attention of the national AIDS programme and link PMTCT programmes with treatment programmes.

Box 35

Key resources: *Guidance on Ethics and Equitable Access to HIV Treatment and Care (WHO/UNAIDS, 2004)*

This document provides guidance on the ethical issues that arise in the scale-up of ART and other HIV-related treatment and care programmes. It aims to help the people concerned with planning and implementing these programmes to: have a frame of reference for public discussion of the programmes; design policies and programmes through a process that is fair to all; and achieve results that are ethically sound and meet human rights obligations. The goal is to create ART programmes that produce the greatest possible good and that distribute benefits equitably.

See www.who.int/ethics/en/ for: (1) a copy of the Guidance; (2) the summary of the *Consultation on equitable access to treatment and care for HIV/AIDS*; and (3) *Equity and Fair Process in Scaling Up Antiretroviral Treatment: Potentials and Challenges in the United Republic of Tanzania*.

Advocate greater domestic and international funding for universal access

Increased domestic spending and international cooperation, as well as a comprehensive, long-term funding plan, are vital to realizing equitable access to care, treatment and support to all in need. See Chapter 4 for details about what parliamentarians can do.

The uncertainty of aid commitments undermines long-term planning and presents serious clinical and ethical problems in relation to financing scale up of treatment, which once initiated must be guaranteed over the course of a patient's lifetime.

– Stop AIDS Campaign, 2007

Strengthen health systems

Addressing the shortage of doctors, nurses and community health workers who can provide HIV care and prevention requires increased financial investments, coordinated policy reforms, and removal of fiscal limitations on national health-related expenditures. Among other activities, **parliamentarians in low- and middle-income countries** can do the following.

- Ensure that countries **devote a greater proportion of national budgets to health** so that they can make sustained efforts towards broader health system strengthening.
- Advocate, and participate in, the development of a **comprehensive and costed plan and programme for recruiting, training and retaining health workers**.
- Ensure that **health workers are targeted for prevention and treatment programmes**.
- Review and reform legal, regulatory and administrative frameworks to allow for task-shifting, where needed, to less specialized and skilled health sector, social system and community workers.
- **Ensure that community- and home-based care is recognized** as a key service in the response to HIV. However, the work of those providing community- and home-based care (largely women and girls) tends to be unrecognized, unpaid and, often, exploitative. Building on existing community initiatives in a way that supports caregivers, rather than burdening them further, is vital. Critical to the sustainability of these services is the ability to link them with public health services.

Parliamentarians in high-income countries can help ensure that health systems in low- and middle-income countries are financed sustainably and predictably over the long term.

- **Advocate increased bilateral budget support to the health sector**, particularly through sector-wide approaches, in order to support long-term national plans for scale-up of basic health services in low- and middle-income countries.

- **Encourage abolition of user fees for basic health services**, and provide support to low- and middle-income country governments to help ensure that the public's inability to pay is not a barrier to access.
- **Ensure that UNAIDS, WHO, UNDP and other concerned agencies are sufficiently resourced** to provide the technical capacity-building needed to strengthen health systems and promote access to affordable HIV pharmaceuticals.
- Leverage your countries' positions on the International Monetary Fund (IMF) board to **ensure that macro-fiscal policy allows for greater flexibility for countries** to undertake expanded investment in the public health and social sector.
- **Advocate the abolition of recruitment policies that explicitly target health workers from low- and middle-income countries, attracting them to high-income countries**; ensure that health professional training programmes in high-income countries are properly resourced so that high-income countries do not have to rely on immigration from low- and middle-income countries to staff their health systems and social sectors.

Strengthen services, support and protection for people living with HIV and their caregivers

- Promote home- and community-based care, community HIV clinics and peer support and counselling groups for people living with HIV.
- Ensure that care and support programmes are costed and budgeted. Mainly women caregivers continue to subsidize national responses to HIV at great personal cost to themselves; yet care and support programmes are often an afterthought, do not realistically take into account the contributions of women and families, and are not sufficiently costed and budgeted. Help governments to adequately cost care and support programmes in national responses.
- Encourage the transformation of caregiving roles – by, for example, promoting the greater engagement of men and communities. Speak out about the burden of caregiving on women and girls, the positive role men can play as caregivers in the context of the epidemic, and the broader community responsibilities in highly affected areas. Work with home-based care programmes to actively reach out to men and to better support wide community involvement.
- Encourage economic empowerment, social assistance, provision of training and community programmes that address the impact of HIV and the burden of care on women and girls. Meet with networks of people living with and affected by HIV – particularly women's organizations – to find out

more about their needs. Facilitate meetings between civil society and government officials on the creation of economic empowerment schemes, social security benefits, micro-credit and community programmes that respond to the needs of individuals and families affected by HIV.

- Ensure that care and support include psychosocial support, and access to palliative care for pain control. Universal access also includes access to cheap, simple pain-relieving and other palliative drugs and interventions, as well as psychosocial support. Yet, in practice, access to such services and commodities is all too often non-existent.

Reform laws and policies that create barriers to treatment and care

Box 36

What do the *International Guidelines on HIV/AIDS and Human Rights* say about access to treatment, care and support?

According to Guideline 6 (as 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 ... adequate ... care information, and safe and effective medication at an affordable price. States should also take measures necessary to ensure for all persons ... the availability and accessibility of quality goods, services and information for ... treatment, care and support, including antiretroviral and other safe and effective medicines, diagnostics and related technologies for ... curative and palliative care of HIV and related opportunistic infections and conditions”.

Remove trade barriers blocking access to medicines

Parliamentarians in low- and middle-income countries can take significant measures to remove trade barriers.

- **Reform national intellectual property legislation to ensure that TRIPS flexibilities are incorporated into national laws and regulations without delay** (see Box 37). When patent protection is more extensive than what is required under the global trade rules (i.e. TRIPS Agreement, WTO *Doha Declaration on TRIPS and Public Health*, WTO December 2005 Decision) and does not balance the rights of the patent-holder with the public health interests, patents can impede access to medicines. To date, relatively few countries have implemented the TRIPS flexibilities, due to a variety of reasons (including lack of awareness of, or understanding about, the available flexibilities, lack of legal expertise on issues related to intellectual property in government departments, inappropriate or inadequate laws on TRIPS flexibilities, and trade policies in some high-income countries and pharmaceutical companies that do not favour use of the TRIPS flexibilities to enhance access to affordable generic medicines).

- **Reform national patent laws in least developed countries to allow national authorities the option of not providing any patent protection in the pharmaceutical sector until 2016, as provided in the WTO *Doha Declaration*.**
- **Encourage regional cooperation to:**
 - develop intellectual property and trade policies and laws that promote innovation, are consistent with global agreements such as TRIPS (which the country has entered into) but that allow for the full use of all flexibilities to ensure access to affordable generic HIV medicines for all who need them;
 - explore joint compulsory licensing applications, particularly in African countries served by regional or subregional patent institutions;
 - promote regional trade in generic medicines;
 - undertake drug registration, to ensure marketing of high-quality drugs, with preferential and expedited registration of medicines pre-qualified by WHO;
 - invest in regional and national productive capacity in the pharmaceutical sector and the development of local expertise.
- **Take an active role in trade negotiations to ensure that their governments do not enter regional or bilateral trade agreements that include intellectual property provisions with more extensive patent protection than required by the TRIPS Agreement (i.e. ‘TRIPS-plus’ provisions), where these provisions undermine the use of TRIPS flexibilities to improve access to affordable medicines.**

Parliamentarians in high-income countries can:

- call upon their government and international agencies to provide all necessary financial, political and technical assistance to ensure that the TRIPS flexibilities can be used and that trade sanctions are not threatened or imposed by their governments upon countries that use the TRIPS flexibilities for greater access to affordable generic HIV medicines and other essential pharmaceuticals;
- oppose any provisions in bilateral, regional or multilateral treaties that create more extensive intellectual property protection (‘TRIPS-plus’) or undermine the flexibilities in the TRIPS Agreement;
- call for a review of the effectiveness of the TRIPS flexibilities to identify and resolve all obstacles to their use.

Reform other laws that create barriers to universal access

- **Reform legislation and tax codes, where needed, to exempt HIV treatment (and prevention) commodities, including HIV medicines, as well as other essential medicines, from all taxes and tariffs.**
- Reform legislation and regulations, as necessary, to ensure that medicines pre-qualified by WHO, or approved by other widely recognized stringent drug-regulatory bodies, can be given provisional marketing approval so that access to HIV medicines and diagnostics is possible, prior to full registration by national drug regulatory authorities.

Support innovative approaches to research and development of pharmaceuticals of value in low- and middle-income countries

Patents are an important incentive in the research and development of pharmaceuticals. The absence of a vaccine and other prevention technologies (such as microbicides), combined with the need for new and simpler treatment regimens, as well as the problems of drug resistance and treatment failure, mean that incentives for innovation in HIV prevention and treatment commodities remain crucial in the response to AIDS. While important scientific advances have been made in recent years in the development of new antiretrovirals, not all of the newer products are suitable for use in low- and middle-income countries because of high prices or complexity in storage or administration. In the area of prevention technologies, such as microbicides, assistance from private philanthropic organizations has been required to boost funding for research, in the absence of adequate investment from governments or the pharmaceutical industry.

Innovation is needed not only for the development of new medicines and technologies themselves, but also in the mechanisms through which research and development of HIV pharmaceuticals and prevention technologies are funded. For example, the Bill and Melinda Gates Foundation has created a global network of 16 different research organizations under a different research and development paradigm known as the Collaboration for AIDS Vaccine Discovery. The conditions of participation in this grant programme are designed to facilitate a new level of open collaboration among the researchers, including prompt sharing of new scientific information within the Collaboration and with the broader scientific community. Such novel approaches to research and development offer the potential of a more efficient mechanism for developing an HIV vaccine suitable for use in low- and middle-income countries and globally. Parliamentarians in all countries should support the exploration of new and different types of incentives and tools to stimulate innovation in the development of new and improved HIV pharmaceuticals.

Box 37

What flexibilities exist under the TRIPS Agreement?

Member countries of the WTO are bound by the requirements of the *Agreement on Trade-Related Aspects of Intellectual Property Rights* (TRIPS Agreement, or TRIPS). The TRIPS Agreement contains comprehensive minimum standards in various areas of intellectual property, including patent protection.

The TRIPS Agreement requires WTO members to establish, among other things, basic criteria of patentability (novelty, inventive step, and industrial applicability) and a minimum patent term of 20 years. Developing countries were bound to fully implement their TRIPS obligations, including pharmaceutical patents, no later than 1 January 2005. Countries defined as least developed countries (LDCs) by the UN had at least until 1 January 2006 to implement TRIPS obligations. For pharmaceutical patents and test data protection, the *Doha Declaration* (see below) extended this transition period until 2016. Therefore, LDCs do not have to grant or enforce local patents until 2016.

To affirm and enhance flexibilities contained in the TRIPS Agreement, WTO Members adopted the *Declaration on the TRIPS Agreement and Public Health* at the Doha WTO Ministerial Conference in November 2001. The *Doha Declaration* stresses that the TRIPS Agreement “can and should be interpreted and implemented in a manner supportive of WTO Members’ right to protect public health and, in particular, to promote access to medicines for all” and underscores existing flexibilities for that in the Agreement. The Declaration unambiguously reconfirms the key flexibilities provided by TRIPS:

- compulsory licensing, including but not limited to cases of national emergency or extreme urgency, and where the public health system provides the medicine for no commercial gain
- leaves national authorities free to determine what is a national emergency or urgency
- countries can use whatever parallel importation regimes they deem appropriate, subject only to national laws, which enables them to obtain patented medicines at the lowest price available on the global market.

An issue left unresolved in the Doha Declaration was how to ensure access to medicines in countries with insufficient or no capacity to manufacture the product in question. In August 2003, a waiver was adopted at the WTO to overcome the limitation, anchored in TRIPS, that compulsory licences must be authorized predominantly for the supply of the domestic market of the member granting the licence. The system established under the waiver decision essentially requires the granting of a compulsory licence in the exporting country and imposes notification requirements on the importing country (plus a compulsory licence if the product is on patent in that country). The waiver decision establishes various other conditions as well. In December 2005, the waiver decision was transformed into a permanent amendment of the TRIPS Agreement, currently awaiting ratification by WTO members.

What is compulsory licensing?

Compulsory licences allow for the use of a patent-protected product – in this case, the production, sale, import and export of a generic HIV medicine – without the consent of the patent-holder. Certain procedural and other requirements must be met, as specified in Article 31 of the TRIPS Agreement. Patent-holders receive reasonable compensation through royalty payments. Contrary to frequent misconceptions,

compulsory licences are not a form of pirating, a legal loophole, or a way of stealing intellectual property. Compulsory licences are a legal tool under the TRIPS Agreement, are considered a regular feature of any comprehensive intellectual property legislation, and have been commonly used by industrialized countries such as the United States of America. France authorizes compulsory licences when patented drugs “are only made available to the public in insufficient quantities or quality or at abnormally high prices”. Both private and government entities may apply for a compulsory licence. Countries should design fast, simple procedures for granting compulsory licences, consistent with the TRIPS Agreement, to make full use of this safeguard in promoting access to affordable HIV medicines and other essential pharmaceuticals.

What is parallel importing?

Parallel importation allows a country to shop around for the best price for a medicine on the global market, by purchasing from a third party who has procured the product from the patent-holder or other manufacturer. It is an attractive option for countries when the same medicine is being sold for different prices in different markets. Many European countries, such as the United Kingdom, benefit from significant parallel trade to reduce the overall cost of medicines.

Box 38

Examples of laws, policies and the use of TRIPS flexibilities

In 2003, the **Malaysian** Government authorized a local company to import three antiretroviral medicines. The Minister of Domestic Trade and Consumer Affairs authorized the company to import generic versions of the medicines from India, for the sole purpose of supplying public hospitals. In the authorization letter, the Minister relied on Section 84 of the *Malaysian Patents Act*. The cited provision allows the Minister to authorize a government agency or third person to exploit a patented invention in the case of a national emergency or where the public interest so requires. The authorization contained specific terms and conditions with regard to price, differentiation in shape and colour from the patented product, and labelling of the medicines. The Ministry of Health reported a significant reduction in monthly costs of treatment as a consequence of the introduction of the generic antiretrovirals.

On 5 October 2004, a Presidential Decree was issued in accordance with Article 5 of the **Indonesian** Government Regulation No. 27 of 2004, regarding the Mechanism of Patent Exploitation by the Government. This was in light of “the urgent need of community in the effort to control HIV/AIDS epidemic”. The Presidential Decree No. 83 of 2004, Regarding Exploitation of Patent by the Government on Antiretroviral Drugs, empowered the Minister of Health to appoint a “pharmaceutical factory” as the patent-exploiter on behalf of the government, taking into account the recommendations from the Head of the National Drug and Food Authority. The two antiretrovirals are Nevirapine (for seven years) and Lamivudine (for eight years) and the exploitation period covers the remaining patent-protection term. The Decree also set the “compensation fee” at 0.5% of the net selling value of the antiretrovirals concerned for the patent-holder. Production of the antiretrovirals has resulted in cheaper treatment in government hospitals.

Other countries that have issued compulsory licences for antiretroviral medicines include Brazil, Ghana, Ethiopia, Mozambique, Thailand, Zambia and Zimbabwe.

Various potential exporting countries (including Canada, China, the European Union, India, the Netherlands and Norway) have implemented the 2003 WTO waiver decision in their legal systems, although practical use has so far been very limited. In **Canada**, the *Jean Chrétien Pledge to Africa Act* was the first such effort at reform. It amends the Patent Act by adding a section on "Use of Patents for International Humanitarian Purposes to Address Public Health Problems". The purpose of this amendment is "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". Although the law has been used once for the exportation of an HIV medicine to a low-income country, as recognized by the Canadian Government in 2006, the amendment has failed to meet its overall goals. The Senate Standing Committee on Foreign Affairs and International Trade has recommended that the legislation be amended. The legislation, together with extensive commentary by the Canadian HIV/AIDS Legal Network about how the Act could be amended to "get it right" (*Getting the Regime Right: Compulsory Licensing of Pharmaceuticals for Export. Brief to the House of Commons*. 18 April 2007), can be accessed via www.aidslaw.ca/treatment.

Hold your government to its promises

Governments, through the 2005 World Summit Outcome, the Gleneagles Communiqué of the Group of Eight (G8) industrialized countries and the 2006 *Political Declaration on HIV/AIDS*, have established the **goal of getting as close as possible to universal access to HIV prevention, treatment, care and support by 2010**.

Specifically, in the *Political Declaration*, Heads of State and Government, and representatives of States and Governments:

- committed themselves to "overcoming legal, regulatory or other barriers that block access to effective HIV ... treatment, care and support, medicines, commodities and services" (paragraph 24);
- undertook to "reinforce, adopt and implement ... national plans and strategies ... to increase the capacity of human resources for health" (paragraph 35);
- committed themselves to "finding appropriate solutions to overcome barriers in pricing, tariffs and trade agreements, and to making improvements to legislation, regulatory policy, procurement and supply chain management in order to accelerate and intensify access to affordable and quality HIV/AIDS ... medicines and treatment commodities" (paragraph 42);
- resolved "to assist developing countries to enable them to employ the flexibilities outlined in the TRIPS Agreement" (paragraph 44);
- committed themselves "to intensifying investment in and efforts towards the research and development of new, safe and affordable HIV/AIDS-

related medicines, products and technologies, such as vaccines, female-controlled methods and microbicides, paediatric antiretroviral formulations ... and to encouraging increased investment in HIV/AIDS-related research and development in traditional medicine” (paragraph 45);

- encouraged “pharmaceutical companies, donors, multilateral organizations and other partners to develop public–private partnerships in support of research and development and technology transfer ...” (paragraph 46);
- encouraged “bilateral, regional and international efforts to promote bulk procurement, price negotiations and licensing to lower prices for ... diagnostics, medicines and treatment commodities ...” (paragraph 47).

These commitments build on the *Declaration of Commitment* (2001), in which countries committed themselves to several time-bound care, support and treatment targets, including:

- **By 2003**, ensure that ... strategies ... are developed ... to strengthen health-care systems and address factors affecting the provision of HIV-related drugs ..., affordability and pricing ... and technical and health-care system capacity ... (paragraph 55);
- **By 2005**, develop and make significant progress in implementing comprehensive care strategies ... (paragraph 56);
- **By 2003**, ensure that national strategies are developed in order to provide psychosocial care for individuals, families and communities affected by HIV/AIDS (paragraph 57).

Many countries have failed to live up to these commitments, and parliamentarians should hold their governments to their promises (see the section, Hold the executive to its promises, in Chapter 4, for more details about what parliamentarians can do).

CHAPTER 9

Reducing vulnerability among women

Summary

Why leadership and action for women are so important

- HIV is affecting women in increasing numbers – globally, they comprise almost 50% of people living with HIV.
- Gender inequality, gender-based violence, and the low status of women remain three of the principal drivers of HIV.
- Yet current responses do not, on the whole, tackle the social, cultural and economic factors that put women at risk of HIV, and unduly burden them with the epidemic's consequences.
- To be more effective, responses to HIV must address the factors that put women at risk.

What you can do

- Parliamentarians have a crucial role to play by, among other things: advocating large-scale, sustained, and well-planned efforts to improve the status of women; advancing policies, laws and budgetary allocations for women-friendly health, social and support services; advancing laws and policies that affirm and protect the rights of women on issues such as domestic violence, equality in marriage, HIV-related discrimination and property and inheritance rights; advancing policies to support new HIV prevention options for women; and lobbying for greater representation of women in parliaments.

Why are leadership and action for women so important?

Women are disproportionately affected by HIV

Globally, and in every region, more adult women (aged 15 years or older) than ever before are living with HIV. The estimated 15.4 million women living with HIV in 2007 represented an increase of over 1 million compared with 2004. In sub-Saharan Africa, for every 10 adult men living with HIV, there are about 14 adult women who are infected with the virus. In some countries, young women and girls can be 4–13 times more likely to be HIV-infected than young men. In the Caribbean, the Middle East, North Africa and Oceania, almost 50% of adults with HIV are female. Meanwhile, in many countries of Asia, Eastern Europe and Latin America, the proportions of women living with HIV continue to grow. Women also disproportionately experience the impoverishment caused by AIDS and the burden of caregiving.

There has to be legislation on sexual violence and rape, on property and inheritance rights, on quotas for parliamentary representation and on the elimination of user fees since they hamper women's access. The failure of the international community generally to respond to women has never been more dramatic than in the face of the pandemic.

– Stephen Lewis, then UN Secretary-General's Special Envoy for AIDS in Africa, 2006

The needs of women are not being addressed in national responses to HIV

Millions of women are becoming infected with HIV because they are denied information and education about HIV, as well as equal access to the commodities and services to prevent infection. The discrimination that girls face in access to education denies them the strong protective effect that education has been shown to have against HIV.⁹⁴

Discrimination against women makes them extremely vulnerable to HIV and to the impact of AIDS

In many countries, national laws restrict women's ability to own, inherit or dispose of property. Women suffer inequality in access to education, credit, employment and divorce. Legal and social inequality renders women economically dependent on their husbands, leaving them little choice but to remain in relationships where they cannot refuse sex or insist on condom use. Women often sink into poverty upon the death of their husband or the dissolution of their marriage, finding their choices and possibilities so diminished that they have to trade sex for survival, or rely on situations of lodging or work that expose them to sexual abuse or violence. Each of these factors places women at a heightened risk of HIV infection. Yet current responses to HIV do not, on the whole, tackle the social, cultural and economic factors that put women at risk of HIV, and that unduly burden them with the epidemic's consequences.

The factors that continue to put women at risk must be addressed

Governments have repeatedly declared their commitment to improve the status of women and acknowledged the linkage with HIV. In some areas, progress has been made. By and large, though, efforts have been small-scale, half-hearted and haphazard. For the response to the epidemic to be successful, much more needs to be done to enable and empower women and men to practise safe and responsible sex, avoid activities and relationships that threaten them with infection, and have the legal, economic, social and health opportunities to avoid HIV or withstand the impact of AIDS. This involves significantly reorienting national HIV responses to support women's equality inside and outside the home, protect women and girls

from violence, and change gender normsⁱⁱ that put men and women at risk. It also involves protecting women from sexual harassment and violence in the workplace through laws, policies, and procedures for resolving grievances. Workplace education and information programmes should empower women to understand their rights and protect themselves both within and outside the workplace.

In a number of countries, there is significant action to empower women and girls with regard to HIV and address harmful gender norms that make men and women vulnerable to HIV. Despite this good work, responses to HIV largely ignore the fact that many women and girls are not accorded equality in law or practice and that this makes it impossible to avoid unwanted sex and violence, or to receive the information, education and health services that will help keep them and their infants free of HIV.

Programmes need to dedicate significant resources to:

- empower women and girls through law reform and legal support;
- social mobilization and economic empowerment schemes;
- campaigns against violence and inequality, harmful traditional practices, and intergenerational sex;
- the provision of female condoms;
- the integration of HIV into sexual and reproductive health services;
- the prevention of early marriage;
- efforts to keep girls in schools and to provide them a good education;⁹⁵
- securing schools as learning environments free of sexual violence for girls.

Men and boys have a major role to play in addressing the gender driver of the AIDS epidemic. In many places, men, like women, also have unrealized rights to HIV-related health information, services and modalities, such as condoms, and freedom from violence. They also have a responsibility to practise safe and violence-free sex and to protect their own health and that of their partners and children. Therefore, HIV responses need to expand ways to bring men and boys into health services, or ensure that boys and girls receive sexual and life skills education that teaches gender equality and non-violence. There needs to be significant investment in programmes to

ⁱⁱ **Gender norms** refer to learned and evolving beliefs and customs in a society that define what is “socially acceptable” in terms of roles, behaviours and status for both men and women. In the context of the HIV epidemic, these gender norms strongly influence both men’s and women’s risk-taking behaviour, expression of sexuality, and vulnerability to HIV infection and impact, including their ability to take up and use HIV prevention information and commodities, as well as HIV treatment, care and support. Gender norms can also be the basis of discrimination and violence against men who have sex with men, lesbians and transgendered people, placing them at higher risk of HIV infection and impact.

transform harmful concepts of masculinity, and to fully support both men and women in the use of condoms, reduction in the number of sexual partners, and access to sexual and reproductive services and HIV testing, counselling and treatment programmes.⁹⁶

Violence against women fuels high rates of HIV infection among women and is epidemic in some countries and communities

Violence and the fear of violence can deter women from seeking HIV testing, insisting on condom use, or disclosing their HIV status to their sexual partners. Many countries do not recognize the crime of marital rape. Even where laws prohibit violence against women, these laws are often not enforced. In many jurisdictions, survivors of rape and sexual violence have little hope of redress for such crimes due to inadequate police investigation, as well as bias and corruption on the part of the judiciary. Sexual violence survivors also rarely gain access to post-exposure prophylaxis for HIV infection.

Current prevention options for women are not enough

Over 25 years into the HIV epidemic, there is still no widely available technology that women can both use and control to protect themselves from HIV. There is a critical need to develop prevention options that women can use with or (when necessary) without their partner's knowledge. This will require increased investment in scientific research on microbicides. (Microbicides are products being developed and tested that women could apply topically to the vagina to reduce the transmission of HIV during sexual intercourse. Microbicides could take the form of a gel, cream, film, suppository, sponge or vaginal ring that releases the active ingredient gradually. Microbicides would block or disable HIV from the moment it enters the body, before it spreads). It will also require greater access to, and promotion of, female condoms.

For many women, health systems remain places of prejudice and discrimination, rather than treatment and care

Access to comprehensive reproductive health services, which is the core of HIV prevention for women and girls, remains woefully lacking and restricted by law and practice in every region of the world. Women are often blamed and abused when they are known to be HIV-positive, which deters them from seeking HIV testing or treatment. Women who become pregnant while living with HIV often encounter judgement and recrimination by health-care workers, rather than being offered proven treatment to prevent mother-to-child transmission of HIV.

Box 39**Key resources on women and HIV***The Global Coalition on Women and AIDS*

The Global Coalition on Women and AIDS was launched in 2004 to respond to the feminization of the HIV epidemic and a growing concern that existing strategies did not adequately address women's needs. The Coalition is an alliance of civil society groups, networks of women living with HIV, and UN agencies, advocating increased programming in several areas:

- preventing new HIV infections by improving access to reproductive health care
- promoting equitable access to HIV treatment and care
- ensuring universal access to education
- securing women's property and inheritance rights
- reducing violence against women
- ensuring that women's care work is properly supported
- advocating increased research and funding for female-controlled HIV prevention methods, such as female condoms and microbicides
- promoting women's leadership in the response to HIV.

➔ **For more information and access to a large number of publications on women and HIV, see:**
<http://womenandaids.unaids.org>.

The Nairobi 2007 Call to Action

At the July 2007 World International Women's Summit in Nairobi, participants adopted the *Nairobi Call to Action on Women and AIDS*, which calls for action to promote the leadership of women and girls; secure their human rights; ensure women's equitable representation in decision-making; and expand resources for women.

For a copy of the *Call to Action* and other materials related to women and HIV, see:

www.worldywca.info/index.php/ywca/world_council_07/iws_women_s_summit.

What parliamentarians can do

Advocate and promote action on women's issues

- Discuss the issue in parliamentary committees concerned with health, social and women's issues, as well as political, community and women's groups, men's and young people's associations, and health and social workers.
- Help people understand how gender-based inequality, poverty and discrimination put women at greater risk of HIV.
- Take a firm stance against harmful norms and behaviours that perpetuate violence against women.
- Emphasize the crucial role of men and adolescent boys in fighting gender inequalities, supporting them to recognize the negative effects of gender inequalities on their own lives, and changing how they view and treat women and girls.

- Encourage faith communities to be a just and compassionate voice for all women and girls, especially HIV-positive women and girls.

Advance services and support for women

- Use your influence in the legislature to advance policies, laws and budgetary allocations for women-friendly health, social and support services – both for protecting women from getting infected and for preventing transmission to their children. These services include voluntary and confidential counselling and testing, services for family planning, reproductive health and safe motherhood, and ART and other means of preventing transmission to babies.

Promote women’s economic security

- Use your influence to ensure that strategies and programmes that promote economic and educational opportunities for girls and women (including credit programmes, skills training, literacy, and secondary and vocational education) are core components of all national HIV prevention and mitigation strategies.
- Advocate the creation of safe shelters and provision of legal and social support for women who have lost, or are at risk of losing, their land or other assets.

Secure legislative and policy changes to protect the rights of women

Laws and policies that affirm and protect the rights of women are vital to the success of the AIDS response. Some countries have passed important legislation on issues such as domestic violence, equality in marriage, HIV-related discrimination, and property and inheritance rights. Yet strategies to enforce these laws and finance their implementation are rare. Women’s rights need to become women’s realities. Parliaments and their members should lobby for the implementation of international agreements on gender equality and the protection of women’s human rights, and for laws that uphold these.

- **Secure legislative and policy changes to protect women and girls from harmful traditional practices.** In traditional African communities, the continued practice of wife inheritance and widow ‘cleansing’ violates women’s human rights and contributes to the spread of HIV. Wife inheritance and cleansing rituals are customary practices common in some communities in sub-Saharan Africa. These practices vary from community to community. In wife inheritance, a male relative of the dead husband typically takes over the widow as a wife, often junior to other wives. In some

forms of ritual cleansing, a widow has to have sex with a social outcast who is paid by the dead husband's family – supposedly to cleanse the woman of her dead husband's evil spirits. While women theoretically can refuse to participate in these activities, in practice, there is great social pressure to comply. Women who refuse risk theft of their land and property by in-laws, banishment from their communities, and other forms of social disgrace. Female genital mutilation violates women's dignity and bodily integrity and exposes them to serious health risks. Because female genital mutilation is often performed in unhygienic conditions, with the same equipment used on many girls, it is thought that it may facilitate HIV transmission. Additionally, lasting damage to the genital area can increase the risk of HIV transmission during intercourse later in life.

- ❑ **Secure legislative and policy changes to protect women and girls from violence. International human rights law obligates nations to ensure that women are not subjected to gender violence.** The UN Committee on the Elimination of Discrimination against Women recommends that States implement legal measures, including penal sanctions, to protect women from all kinds of violence. Many States have responded by enacting legislation criminalizing rape, domestic abuse and sexual harassment. However, because gender violence and sexual harassment encompass so many forms of abuse, no single legal or policy approach can protect women effectively and punish the perpetrators of the crimes. Indeed, the successful implementation of protection against sexual harassment and violence can be elusive in many societies where women are not socially or economically empowered to protect themselves.
- ❑ **Secure legislative and policy changes, where needed, to protect women against marital rape.** Married women are at high risk of contracting HIV in countries where transmission occurs primarily through heterosexual sex, and cultural norms condone male promiscuity or patriarchal control of the married couple's sexual activity. Trauma and tissue-tearing caused by forced sex can increase the likelihood of HIV transmission. A number of countries have criminalized marital rape in recent decades, adopting laws acknowledging that marriage does not signify an agreement to sexual intercourse at any time and that married women have the right to refuse sex with their husbands. Such laws are important. However, they alone are not sufficient to protect women from contracting HIV. Societal norms in many countries dictate that women are inferior to men, and customary law often does not recognize marital rape. Since women in such countries lack the power to negotiate sex and safer sexual practices, laws that contribute to the marginalization of women must also be repealed or reformed in an effort to empower women against marital rape.

- **Secure legislative and policy changes to ensure equality in domestic relations, including in respect of property and inheritance rights of women and girls, and to promote access to credit, skills training, education and employment opportunities for women and girls.** In many low-income countries, statutory and customary laws prevent women from owning, controlling or inheriting property. Upon dissolution of a marriage or death of a spouse, women often lose control over all significant assets. Exclusion from full property rights carries particularly harmful consequences for divorced or widowed HIV-positive women, who may be forced into poor or unsanitary living conditions or may no longer be able to afford treatment. In some circumstances, divorced or widowed women who have no property or job prospects may have to resort to sex work to support themselves, thereby increasing their risk of contracting HIV.
- **Secure reproductive rights.** Reproductive rights encompass individuals' freedom to determine the number, spacing and timing of their children; the right to access the information necessary to make such determinations; and the right to the highest available standard of sexual and reproductive health. HIV-positive women face numerous barriers to the realization of these rights, including both laws and informal practices that restrict reproductive freedom. Many of these restrictions (such as forced or coerced sterilization, recommended abstinence from sex and childbearing, and compulsory HIV testing) are designed to prevent the birth of HIV-infected children. However, with access to appropriate reproductive health care, counselling and treatment, HIV-positive women are able to engage in sex and childbearing with minimal risk of transmission to their partners or infants. Reproductive rights require governments to minimize restrictions on reproductive liberty and maximize access to resources that enhance autonomous reproductive decision-making.
- **Strengthen the legal and policy environment** to ensure that such laws are not only enacted but enforced, that systems for reporting on the prevalence of violations are established and maintained, and that these monitoring mechanisms effectively feed into the design of national AIDS programmes.
- **Advocate investments in strategies to educate the police, the judiciary, social service providers, civil servants and community leaders about laws and their legal responsibilities.**
- **Advocate measures to empower women to understand their rights and promote more equal gender relations at the workplace.**
- **Advocate appropriately funded programmes to improve legal aid services and other forms of support so that women can claim their rights.**

- **Oppose laws and policies that violate rights and have limited protective effect, such as mandatory premarital testing.** Instead, expand ways to protect women and girls against HIV infection in the context of marriage. In many places, women are most vulnerable to infection and to negative consequences upon disclosure of an HIV-positive status in the context of marriage. In an attempt to protect women, some jurisdictions are implementing mandatory premarital testing that violates rights and has limited protective effect. Meet with women's groups to explore ways of better protecting women in the context of marriage. Alongside integration of HIV into sexual and reproductive health services, these could include campaigns against early marriage, policies to provide or require voluntary premarital HIV counselling and testing, and expansion of programmes for couples counselling and testing.

Box 40

Key resources: Model legislation on women's rights in the context of HIV in sub-Saharan Africa

The Canadian HIV/AIDS Legal Network has developed model legislation on four aspects of women's rights: rape/sexual assault; domestic violence; marriage, divorce and cohabitation; and inheritance.

For more information and a copy of the model legislation, see: www.aidslaw.ca/women

Box 41

Examples of laws and policies on harmful traditional practices, gender violence, marital rape, the right to own and inherit property, and reproductive rights

Harmful traditional practices

Some **African countries** have begun a process of legal reform in this area. For example, parliaments have considered bills that would criminalize wife inheritance. However, a purely legal approach without adequate education and enforcement is unlikely to result in rapid abandonment of valued traditional practices. A complementary effort should be made to encourage ethnic and tribal leaders to replace wife inheritance and widow 'cleansing' with less risky rituals. There is some evidence demonstrating the effectiveness of such an approach. In **Malawi**, after unsuccessfully attempting to ban widow 'cleansing', health officials convinced traditional leaders to encourage the use of condoms for those who are involved in the rituals. Some local tribal leaders have welcomed the initiative, modifying customary law to punish cleansers who force women to have sex without condoms.

In 2005, the Government of **Zambia** amended the penal code to make it illegal for any person to engage in a harmful cultural practice such as widow 'cleansing', or to encourage another person to engage in the practice. This national-level law reform supports ongoing changes to policies and practices at the local levels. The AIDS Care

and Prevention Department at Chikankata Hospital began promoting alternative ritualistic methods of sexual 'cleansing' through a process of consultation with local chiefs. These consultations explored alternatives to ritualistic cleansing, such as non-sexual practices or protected sexual practices (during which condoms are used). Subsequently, the chiefs in the Chikankata Hospital area enacted a law to abolish ritual cleansing by sexual intercourse in the early 1990s.

Many countries have enacted statutes that specifically prohibit female genital mutilation, whereas others have relied upon existing criminal codes that assign penalties to practices that can be interpreted to include female genital mutilation.

Gender violence

South Africa passed a number of progressive laws designed to prevent gender violence. The 1998 *Domestic Violence Act* criminalizes non-consensual sex within marriage and violence in both marital and non-marital relationships. The Act imposes duties on the police to provide necessary assistance, including arrangements for suitable shelter and medical treatment, to victims of domestic violence, as well as information about their rights; there are sanctions for non-compliance with these duties. South Africa also established specialized sexual offences courts that aim to: reduce the trauma experienced by sexual assault complainants during the investigations and prosecution processes; improve coordination among criminal justice agencies; and increase the reporting, prosecution and conviction rate for sexual offences.

In the **Philippines**, the investigation of offences committed against women must be handled by an all-female team of police officers, examining physicians and prosecutors. Protective measures, such as the right to privacy and closed-door investigations, are accorded to the victim.

In **Namibia**, the *Combating of Domestic Violence Act* covers various forms of domestic violence, including sexual violence, harassment, intimidation, economic violence and psychological violence. The law authorizes several alternatives to filing criminal charges against perpetrators of domestic violence. Those who have suffered violence may use a simple, free procedure to request a protection order from a magistrate's court, directing the abuser to stop the violence, prohibiting the abuser from having any contact with the victim, or ordering the abuser to leave the common home. In addition, the law contains provisions designed to protect the privacy of a complainant who brings a criminal charge and to make the court process less traumatic.

Marital rape

In **Mexico**, the Supreme Court overturned a 1994 decision that characterized violently forcing a spouse to have sex as the exercise of a conjugal right. The court declared that forced sex within marriage is considered rape and is punishable by law.

In **Zimbabwe**, the *Sexual Offences Act* of 2001 considers non-consensual sex within marriage as rape.

The Supreme Court of **Nepal** decided in 2002 that husbands who force their wives to have sex can be charged with rape. The court cited both international human rights obligations and religious texts in support of its decision.

Right to own and inherit property

In the **United Republic of Tanzania**, the 1999 *Land Act* and *Village Land Act* include provisions overriding customary laws that restrict women's rights to use, transfer and own land. In addition, the Acts ensure that women are represented in land administration and adjudication bodies.

Reproductive rights

South Africa's Constitution (adopted in 1996) specifically guarantees citizens' reproductive rights. Section 9(3) outlaws discrimination on the grounds of pregnancy; section 12(1)(c) states that everyone has the right "to be free from all forms of violence from both public and private sources". This clause guarantees bodily and psychological integrity, which specifically includes the right "to make decisions concerning reproduction" and "to security and control over bodies".

UNAIDS and UNFPA, together with other civil society groups and NGOs, issued the *New York Call to Commitment Linking HIV/AIDS and Sexual and Reproductive Health* in 2004. This statement reiterates the important linkages between AIDS and sexual and reproductive health, calling on countries to improve education and access to services around sexual and reproductive health. See

<http://www.unfpa.org/publications/detail.cfm?ID=195&filterListType=3>

For more details and additional examples, see: World Bank (2007). *Legal Aspects of HIV/AIDS, A Guide for Policy and Law Reform*: siteresources.worldbank.org/INTHIVAIDS/Resources/375798-1103037153392/LegalAspectsOfHIVAIDS.pdf.

Hold the executive to its promises

In the *Declaration of Commitment on HIV/AIDS* (2001), countries committed themselves to the following targets.

- **By 2005**, implement strategies that: promote the advancement of women and women's full enjoyment of all human rights; promote shared responsibility of men and women to ensure safe sex; and empower women to protect themselves from HIV infection, including by providing prevention and health information (paragraph 59);
- **By 2005**, implement strategies eliminating all forms of discrimination and violence against women and girls, including harmful traditional practices, abuse, rape, sexual violence, battering and trafficking (paragraph 61).

Recognizing that many countries had failed to reach these targets, in the **2006 Political Declaration on HIV/AIDS**, Heads of State and Government, and representatives of States and Governments renewed their commitment to "strengthening legal, policy, administrative and other measures for the promotion and protection of women's full enjoyment of all human rights and the reduction of their vulnerability to HIV/AIDS through the elimination of all forms of discrimination, as well as all types of sexual exploitation of women, girls and boys, including for commercial reasons, and all forms of violence against women and girls, including harmful traditional and customary practices, abuse, rape and other forms of sexual violence, battering and trafficking in women and girls" (paragraph 31).

Mobilize national and international resources for programmes and interventions that work for women

- Advocate increased funding from national governments and international donors for programmes to address gender inequalities that fuel the epidemic among women and girls, while promoting efforts to reform and enforce legislation to protect, and ensure equality of, women and girls.
- Advocate increased funding for microbicide research, development and large-scale clinical trials.
- Promote public and private sector investment in female condoms.

Allocate more seats at the table to women

- Advocate a review of membership of national AIDS coordinating bodies and other relevant decision-making and consultative forums to ensure the meaningful representation of women and people with gender expertise.
- Step up the representation of women in parliaments.

There is evidence ... that issues that affect the family, children, mothers and women in general receive much more attention in parliaments with a higher proportion of women. All our parliaments should aim at having at least 30 percent women to start with and then move on to at least 40 percent.

– Professor Miriam Were, Director National AIDS Control Council, Kenya, 2005

CHAPTER 10

Reducing vulnerability among children

Summary

Why leadership and action for children are so important

- Over 25 years into the epidemic, children remain at grave risk. As of 2007, 2.5 million children under 15 years old were infected with HIV, 15.2 million children under 18 had lost one or both parents to AIDS, and millions more had been made vulnerable.
- Children affected by HIV may experience poverty, homelessness, school drop-out, discrimination, loss of economic and social opportunity, and early death.
- Progress remains unsatisfactory in prevention, diagnosis and treatment of HIV in children.
- Countries are not adequately fulfilling their commitments to provide care and support for vulnerable children.

What you can do

- Parliaments and their members are taking many actions to ensure that the needs of children are not overlooked when strategies on HIV prevention and treatment are drafted, policies and laws made, and budgets allocated – but they can do more.

Why are leadership and action for children so important?

Hardly anyone disputes children's right to HIV prevention, care and treatment. Nevertheless, in general, too little effort is being made to ensure that children receive the services they need. All actors, including parliaments and their members, must demonstrate leadership and act now to keep the next generation free of infection.

We have the influence, and we command the national resources, that will roll back this pandemic.

Parliamentarians can not only tackle the fear and prejudice that fuel the epidemic, but we can ensure that public officials fulfil their responsibilities towards HIV-positive children by providing treatment without discrimination.

– IPU President Pier Ferdinando Casini, 2006

Large numbers of children are dying of AIDS

Every minute of every day, more than one child under the age of 15 dies of AIDS-related illness. AIDS claimed 2.1 million lives in 2007, 330 000 of them children under the age of 15.

Increasing numbers of children are infected with HIV

In 2006, 530 000 children under 15 were newly infected with HIV.

Without treatment, half of the children that contract HIV during their mother's pregnancy or during birth will die before their second birthday.

Many children are missing the chance to start life free of HIV

More than 95% of HIV-positive infants acquire HIV from their mothers in utero, during their delivery, or while being breastfed. Without prevention measures, about 35% of children born to HIV-positive women will contract the virus. Yet high-income countries have reduced HIV infections in young children to 1–2% by combining ART with elective Caesarean-section delivery and the avoidance of breastfeeding. In contrast, only a small number of low- and middle-income countries report adequate coverage of services to prevent mother-to-child transmission of HIV. In most countries, the vast majority of pregnant women and newborns lack access to these services.

Children are missing the medicines they need

Children living with HIV or AIDS are missing out on measures to keep them healthy, such as ART and the antibiotic cotrimoxazole, which has proved to be effective in decreasing child mortality in HIV-positive children. Children provided with these medicines may be able to grow up, into adolescence and beyond, to live relatively healthy and productive lives.

Sadly, most children living with HIV face a very different reality. The number of children with access to treatment has increased significantly, but overall coverage remains low in most low- and middle-income countries. Only 15% of the children living with HIV in low- and middle-income countries who could be benefiting from ART were receiving it at the end of 2006.

Particularly in sub-Saharan Africa, access to treatment for children is quite low in comparison with adult access. The challenges of expanding access to treatment for children have been considerable, among them the difficulties of diagnosing HIV in infants and the cost and limited range of paediatric drug formulations. Without treatment, these children will almost certainly become ill and die very young.

Increasing numbers of parents are dying, leaving large numbers of orphans and vulnerable children behind

After illness and death itself, the harshest impact on children is the loss of their parents' affection, support and protection. Globally, as of 2005, an estimated 15.2 million children under 18 had lost one or both parents to AIDS.

When bereft of parental or other responsible care because of their parents' illness or death, children are at grave risk – of hunger, of dropping out of school, of losing their inheritance, of drug use, of sexual and mental abuse, and of contracting HIV. Many are forced into child labour in order to sur-

vive and, in the process, lose out on education and other opportunities to learn valuable skills, diminishing future prospects of finding work.

In addition to these orphans, many more children are left vulnerable by HIV, including those who live in households that have taken in orphans, or those who have lost teachers and other adult members of the community to AIDS.

Orphans and other children made vulnerable by HIV are often stigmatized, isolated, discriminated against, disinherited and deprived of basic human rights to education and health.

Children are missing education

In the worst affected countries, AIDS is disrupting the demand for education, and diminishing the supply of teachers and resources available for schools and the quality of teaching. For the poorest households, school fees and the cost of uniforms and educational materials can be prohibitive. As HIV spreads, children are in danger of missing out on the knowledge and confidence necessary to protect themselves and prepare for a full and productive life. In order to address this, the 2005 World Summit resolved to urgently implement a number of initiatives, including the elimination of user fees for primary education. Yet some countries have failed to eliminate these fees. Although there has been some improvement in rates of school attendance, orphans continue to lag behind non-orphans.

In addition, even many of the children who are attending school are missing out on education on HIV, because such education has not been introduced into schools and non-formal education curricula.

Box 42

Additional resources on children and HIV

For more information and guidance on issues related to children and HIV, see:

- World Health Organization (2006). *Taking stock: HIV in children*. Available via <http://www.who.int/hiv/paediatric/en/index.html>. Many other WHO publications on paediatric HIV and treatment of children living with HIV are available at the same address.
- Médecins Sans Frontières (2005). *Paediatric HIV/AIDS. Fact Sheet*.
- Global Movement for Children (2006). *Saving lives: Children's right to HIV and AIDS treatment*. Available via www.gmfc.org.
- See also many publications produced by the campaign, Unite for Children, Unite against AIDS, launched in 2005 by UNICEF: www.uniteforchildren.org.
- See also the *Framework for the protection, care and support of orphans and vulnerable children living in a world with HIV and AIDS*, which sets standards for the care and protection of children affected by AIDS: http://www.unicef.org/aids/files/Framework_English.pdf.

What parliamentarians can do⁹⁸

Break the silence, end ignorance and prejudice, and mobilize resources for children

- At parliamentary committees, political meetings, discussions with NGOs and public forums, draw attention to how AIDS has orphaned millions of children – and made them and other children vulnerable to HIV.
- Press for detailed information and data to monitor the situation of orphans and other vulnerable children.
- Press for the rapid expansion of programmes to prevent mother-to-child transmission.
- Document and publicize how children orphaned by AIDS are often stigmatized and discriminated against, and prevent, challenge and redress such abuses.
- Investigate whether traditional orphan-care systems are coping and examine what support government and communities must provide to ensure good care for orphans and other vulnerable children.

Box 43

An example of leadership and action: AWEPA undertakes a multi-year campaign on children and HIV

In 2004, the Association of European Parliamentarians for Africa (AWEPA) launched a multi-year campaign on children and HIV, in cooperation with UNICEF and others, to scale up the parliamentary efforts on behalf of children, in the context of HIV. In September 2004, the Parliamentary Consultation on Orphans and Vulnerable Children in Cape Town resulted in the *Cape Town Declaration*, which contains guidelines on how parliamentarians can make a unique contribution to scaling up efforts on behalf of orphans and vulnerable children. The declaration includes a plan of action. Parliamentarians committed themselves to, *inter alia*:

- increasing awareness about HIV by speaking up about the issues in their constituencies;
- reviewing and, if necessary, amending all relevant legislation to ensure that the rights of children are protected;
- securing resources for a massive and more effective response to the needs of orphans and vulnerable children.

For additional information about AWEPA's work on HIV and the text of the declaration and action plan, see: <http://www.awepa.org>.

Develop laws and policies that protect affected children

- Introduce or reform policies and legislation to define standards of protection and care for orphans and other vulnerable children, based on the best interests of each child. Fostering and adoption, birth registration, and provision of community-based care are among the key issues that need to be addressed.
- Advocate policies and laws to prevent discrimination against orphans and other vulnerable children, to protect the inheritance and property rights of orphans and widows, and to protect orphans and other vulnerable children from abuse, violence, exploitation and discrimination.
- Recognize that the rights of women are integrally linked to the rights of children, and secure legislative and policy changes to protect the rights of women (see Chapter 9).
- Advocate the full implementation of the *Convention on the Rights of the Child and its Optional Protocols*. If all articles in the Convention were incorporated into national law and implemented, there would be less need for specific measures to protect children affected by, or infected with, HIV.
- Convince other legislators and communities of the wisdom of implementing community-based solutions and responses. Explain to them the reasons why orphans and other vulnerable children should not be sent away or institutionalized. Orphanages and other institutions should only be used as a last resort.
- Show them why programmes and policies that address orphans' needs should include all other vulnerable children – to promote equitable treatment of all children and to shield children, especially those orphaned by AIDS, from stigma and discrimination and other human rights violations.

Develop laws and policies that support prevention of mother-to-child transmission of HIV

- Ensure that policies or laws require that all pregnant women are routinely offered voluntary HIV counselling and testing, but are not routinely or mandatorily tested.
- Ensure that all pregnant women and adolescent girls living with HIV have access to the full range of methods for reducing the risks of transmitting HIV to their infants, including ART, safer delivery practices and safer ways of feeding infants.
- Ensure that programmes to prevent transmission from mother to child are properly linked with HIV-related services for HIV-positive mothers.

Box 44

Examples of laws and policies that protect children living with and affected by HIV

The **Uganda Children Act** bestows special rights and responsibilities on local governments to **protect children's inheritances**: "... every local government council shall mediate in any situation where the rights of the child are infringed and especially with regard to the protection of a child, the child's right to succeed to the property of his or her parents".

The **Kenya Birth and Deaths Registration Act** **requires all births to be registered**. In order to register as many births as possible, the registration service was decentralized down to the level of the smallest administrative units to ensure the registration of home births, and registration was made free of charge.

The OECS (**Organisation of Eastern Caribbean States**) Family Law Reform and Domestic Violence Project has prepared draft model legislation for the region on, inter alia, status of children, adoption, child protection, juvenile justice, and family court.

Malawi has adopted a **National Plan of Action for Orphans and Other Vulnerable Children**, which includes the review and updating of legislation with respect to alternative care, monitoring of alternative care arrangements by the State, involvement of children in decision-making, and facilitating networks of parents trained in the rights and protection of children.

Article 37 of the **Cambodia Law on the Prevention and Control of HIV/AIDS** states, "No **educational institution** shall refuse admission or expel, discipline, isolate or exclude from gaining benefits or receiving services to a student on the basis of the actual, perceived or suspected HIV/AIDS status of that student or his/her family members".

The **Malawi National HIV/AIDS Policy** instructs the government to "strengthen and enforce existing legislation to protect children and young people against any type of **abuse or exploitation**". The Policy also urges the government to ensure that children have adequate information and education for preventing HIV; that counsellors are trained to counsel abused children and provide them with sexual health information; and that youth centres are created to provide safe havens for children to successfully develop.

In **Kenya**, Section 14 of the **Children Act** **prohibits early marriage and other traditional practices likely to harm the child's development**. "No person shall subject a child to female circumcision, early marriage or other cultural rites, customs or traditional practices that are likely to negatively affect the child's life, health, social welfare, dignity or physical or psychological development."

The **National Policy on HIV/AIDS** of **Nigeria** provides that the Nigerian Government's support of orphans and vulnerable children must include **protection for children from "all forms of abuse** including violence, exploitation, discrimination, trafficking, and loss of inheritance".

For additional examples, see: World Bank (2007). Legal Aspects of HIV/AIDS, A Guide for Policy and Law Reform: siteresources.worldbank.org/INT/HIVAIDS/Resources/375798-1103037153392/LegalAspectsOfHIVAIDS.pdf.

Protect, support and strengthen families and communities most affected by AIDS

- Promote and strengthen family and community-based care.
- Ensure that orphans are involved in planning and implementing orphan-related services.
- Give special priority to hard-hit communities for improving health, nutrition, water and sanitation, education, psychosocial counselling, agricultural productivity services and schemes for income-generation.
- Strengthen and support community efforts to identify and monitor vulnerable households and to provide care and support for orphans and other vulnerable children.
- Advocate mechanisms to provide economic support to parents, families and households in distress – for example, through tax relief, reduction or abolition of school and health charges, and the provision of grants for community-based orphan care.

Support programmes that help young people stay in school

- Encourage programmes that help young people stay in school. Evidence has demonstrated that getting and keeping young people in school, particularly girls, dramatically lowers their vulnerability to HIV – provided schools are a place of safety, in terms of sexual violence.
- Ensure that orphans and vulnerable children have equal access to education and receive the support they need to stay in school.
- Advocate the elimination of all fees related to school attendance, and compulsory primary education for both girls and boys.
- Advocate the inclusion in school curricula of education on the basics of HIV transmission, comprehensive sex education and life skills, including negotiating of condom use.

Hold your government to its promises

In 2001, countries recognized that children orphaned and affected by AIDS need special assistance, and committed themselves to reaching the following targets in the *Declaration of Commitment on HIV/AIDS*.

- **By 2005**, reduce the proportion of infants infected with HIV by 20 per cent, and by 50 per cent by 2010, by ensuring that 80 per cent of pregnant women accessing antenatal care have information, counselling and other HIV prevention services available to them ... as well as through effective interventions for HIV-infected women ... (paragraph 54);

- **By 2003**, develop and **by 2005** implement national policies and strategies to build and strengthen governmental, family and community capacities to provide a supportive environment for orphans and girls and boys infected and affected by HIV/AIDS, including by providing appropriate counselling and psychosocial support, ensuring their enrolment in school and access to shelter, good nutrition and health and social services on an equal basis with other children; and protect orphans and vulnerable children from all forms of abuse, violence, exploitation, discrimination, trafficking and loss of inheritance (paragraph 65);
- Ensure non-discrimination and full and equal enjoyment of all human rights through the promotion of an active and visible policy of de-stigmatization of children orphaned and made vulnerable by HIV/AIDS (paragraph 66);
- Urge the international community, particularly donor countries, civil society, as well as the private sector, to complement effectively national programmes to support programmes for children orphaned or made vulnerable by HIV/AIDS in affected regions and in countries at high risk and to direct special assistance to sub-Saharan Africa (paragraph 67).

In the **2006 *Political Declaration on HIV/AIDS***, Heads of State and Government, and representatives of States and Governments renewed their commitment “to addressing as a priority the vulnerabilities faced by children affected by and living with HIV” (paragraph 32). But many countries have failed to reach the targets they agreed to. In his 2006 report on the implementation of the *Declaration of Commitment on HIV/AIDS*, the UN Secretary-General noted that “[n]ational governments, international partners and communities are failing to adequately provide care and support for the 15 million children orphaned by AIDS and for millions of other children made vulnerable by the epidemic.”⁹⁹ Among other things, the Secretary-General pointed out that:

- high-prevalence countries are making some progress in the development of child-focused policy frameworks on HIV, but less than 10% of the children who have been orphaned or made vulnerable by AIDS receive support or services;
- many countries have national policies in place, but commitment to address the additional AIDS-related needs of orphans and other vulnerable children remains low and most of the plans are not adequately funded.

Increased action on the needs of children is a necessary component of countries’ efforts to fulfil their commitment to coming as close as possible to universal access to comprehensive prevention, treatment, care and support by 2010. The MDGs will not be reached without integrating

approaches to children and HIV with approaches to child health and survival.

As part of their broader efforts to hold the executive to its HIV-related promises (see the section, Hold the executive to its promises, in Chapter 3), parliamentarians should track whether their governments are fulfilling the promises they made related to children and, if necessary, demand that their governments live up to these promises.

Mobilize national and international resources for children affected by HIV

- Advocate rapid scale-up of budgetary allocations and expenditures for orphans and vulnerable children and national PMTCT programmes.
- Ensure that national plans of action for orphans and vulnerable children and national PMTCT programmes are fully costed and budgeted.
- Demand a significant role in drafting or revising national policy frameworks such as poverty reduction strategies, medium-term expenditure frameworks, sector-wide approaches and national AIDS strategies, and ensure that they have clear budget allocations and statements of targets to be achieved on behalf of children affected by AIDS.
- Advocate a significant increase in official development assistance overall, but also a bigger proportion allocated to HIV and, specifically, to integrated programmes for children affected by AIDS and for PMTCT programmes.

Advocate affordable medicines for children

- Call for appropriate and affordable medicines, especially formulations and diagnostics adapted to the specific needs of children.
- Call for rapid, in-country registration of paediatric drugs.
- Call upon your government to use the TRIPS flexibilities, as supported by the United Nations General Assembly in its June 2006 *Political Declaration*, when patents are hindering the production or procurement of paediatric formulations (see Chapter 8 for more details about how to use the TRIPS flexibilities).

CHAPTER 11

Reducing vulnerability among young people

Summary

Why leadership and action for young people are so important

- AIDS is increasingly a disease of the young; nearly half of all new infections now occur in young people.
- Young women are especially vulnerable to HIV.
- Many young people do not have access to the HIV-related information, skills and services they need.

What you can do

- Parliamentarians can do much to help address the needs of young people in the context of HIV. Among other things, they can: (1) counter adult prejudices against allowing young people to have access to prevention and education; (2) advocate universal coverage with comprehensive, age-appropriate and evidence-informed sexual and reproductive health education in schools and other settings; (3) remove any legislative barriers to young people's access to HIV counselling and testing and to comprehensive HIV prevention measures and treatment, care and support; and (4) advocate inclusion of young people in the design, implementation and monitoring of HIV programmes that affect their lives.

Why are leadership and action for young people so important?

HIV increasingly affects young people

In many regions of the world, new HIV infections are heavily concentrated among young people (15 to 24 years of age).¹⁰⁰ Every day, nearly 3500 young people become infected with HIV – over 1.2 million a year.

Young women are especially vulnerable to HIV

In some low-income countries, more than twice as many young women as young men are contracting HIV. Girls and women are physiologically more easily infected with HIV during heterosexual intercourse than are men. Older men are also having sex with younger women and girls. The lifelong disadvantages that face girls and women because of gender-based discrimination (including inadequate education, poor pay and employment prospects, and violence, abuse and exploitation by men) make them particularly vulnerable to unwanted, unsafe sex, both within and outside of marriage. Compounding the risks, they are often denied access to critical knowledge and education about sexuality and sexual health. During civil unrest and armed conflict, young women and girls are even more likely to become victims of sexual violence and coercion.

Disadvantaged and ostracized young people are in greatest danger

Young people who are affected by armed conflict, suffer sexual exploitation, are trafficked, are orphans, live on the streets or in institutions or inject drugs, have even less access to information, skills, services and support than other young people. Boys and young men who have sex with men are particularly vulnerable.

Young people lack access to information and services to prevent HIV

Young people often lack access to basic information and services to prevent HIV, as well as independent access to HIV testing, counselling, condoms and treatment. In schools and youth programmes, frank and complete information about sexual and reproductive health is often censored in favour of messages that emphasize only abstinence and sexual morality and ignore the reality that many young people engage in sexual relations. Young people who use drugs (and the social workers and educators working with them on harm reduction and comprehensive prevention approaches) often face legal restrictions on the use of sterile injecting equipment and opioid substitution therapy to prevent HIV.

Young people are the world's greatest hope for defeating HIV

Youth are a powerful prevention resource. Adopting safe behaviour and attitudes is easier if started before patterns are formed. Wherever the spread of HIV has slowed or even declined, it is primarily because young men and women have been given the tools and the incentives to protect themselves against HIV.

Box 45

An example of leadership and action: National Students and Youth Parliament on HIV and AIDS in New Delhi

The Parliamentarians Forum on HIV/AIDS in India organized a Students and Youth Parliament on HIV/AIDS in New Delhi on 6–7 November 2004. The purpose was to empower young people to be leaders in the response to HIV, and to talk about prevention and treatment, care and support needs. Nearly 5000 students and youth leaders from all the states and districts of India attended the event.

The Youth Parliament was inaugurated by Prime Minister Dr Manmohan Singh who told the young audience, "The manner of your coming together confirms that India's democratic institutions provide the best means to fight the worst of the threats."

What parliamentarians can do¹⁰¹

End ignorance about HIV and young people

- Break the silence about HIV by addressing young people themselves, parents, teachers, health and social workers, community members, the media, people of influence and parliamentary committees concerned with young people.
- Use country-specific information to demonstrate how many young people are vulnerable, infected or affected nationally and locally.
- Discuss how and why young people are especially vulnerable to HIV and other sexually transmitted infections, and which young people are most vulnerable.
- Discuss social and cultural issues that are obstacles to prevention, such as gender discrimination, child abuse, sexual exploitation and rape.
- Ask young people what information, services and support they need for counselling, prevention, protection, treatment and care.
- Encourage young people to discuss sexuality, peer and adult pressure, gender discrimination, abuse and other issues that affect their risks of contracting HIV.
- Stress that young people are not a ‘problem’ but an invaluable resource.

Stop fear and prejudice against young people with HIV

- Call for compassion, support and protection for young people living with HIV and those who are especially vulnerable to infection.
- Build bridges between communities and ostracized or marginalized young people so as to end discrimination against them.

Advocate provision of comprehensive sex education

- Call for provision of knowledge and information about sexuality and sexual and reproductive health to young people before they become sexually active. There is overwhelming evidence that the more educated young people are about sex, the better are the chances that they will delay having sex or practise safer sex. Comprehensive sex education can reduce behaviours that put young people at risk of contracting HIV and STIs, or that result in unplanned pregnancies. Studies have also repeatedly shown that this kind of sex education does not lead to the earlier onset of sexual activity among young people and, in some cases, will even lead to it happening later.¹⁰² In contrast, there is no evidence of the effectiveness of abstinence education.¹⁰³

Advocate provision of life skills – because information alone is not enough

Advocate the provision of life-skill-based education:

- to provide young people with the skills to develop healthy attitudes and the negotiating capacity to make informed, healthy choices about sex, drugs, relationships and other issues;
- to motivate them to protect themselves and their peers;
- to empower girls and women to have the confidence and ability to negotiate sexual relationships on an equal basis with boys and men;
- to promote responsible behaviours by boys and men.

Advocate youth-friendly and comprehensive services

- Counter adult prejudices against allowing young people to have access not only to information and voluntary and confidential counselling and testing for HIV, but also to services for harm reduction and prevention of STIs.
- Advocate services that are affordable, welcoming, convenient and gender-sensitive, that link into vocational training and related programmes such as apprenticeships, and that provide education, support and counselling from other young people in peer education programmes.
- Advocate the meaningful involvement of young people in decision-making, particularly regarding HIV prevention strategies for young people.

Secure legislative and policy changes

Laws and policies that facilitate, rather than hinder, young people's access to prevention, treatment, care and support are vital to the success of the HIV response. In particular, parliamentarians can work to secure legislative and policy change to ensure:

- universal coverage with comprehensive, age-appropriate and evidence-informed sexual and reproductive health education in schools and vocational training and through community centres and outreach services;
- that laws or policies do not restrict educational activities around HIV prevention in schools, such as requiring prior consultation with, or approval of, parents for HIV education and information courses to minors;
- increased opportunities for girls to enrol and stay in school, and to access employment;
- gender-sensitive and youth-friendly health and social services, including voluntary and confidential counselling and testing, condoms, sexual and reproductive health services, measures to prevent HIV transmission through injecting drug use, and drug and alcohol use prevention;

- removal of any legislative barriers to young people's access to HIV testing and counselling and to comprehensive HIV prevention measures, including male and female condoms, sterile injecting equipment, and substitution treatment;
- young people's participation in developing and running peer education and HIV-prevention programmes;
- that young people are protected from all forms of abuse, violence, exploitation and discrimination.

Hold your government to its promises

In 2001, countries recognized that young people need special assistance, and they committed themselves to the following targets in the *Declaration of Commitment on HIV/AIDS*.

- **By 2003**, establish time-bound national targets to achieve the internationally agreed global prevention goal to reduce by 2005 HIV prevalence among young men and women aged 15 to 24 in the most affected countries by 25 per cent and by 25 per cent globally by 2010, and intensify efforts to achieve these targets as well as to challenge gender stereotypes and attitudes, and gender inequalities in relation to HIV/AIDS, encouraging the active involvement of men and boys ... (paragraph 47);
- **By 2005**, ensure that at least 90 per cent, and by 2010 at least 95 per cent of young men and women aged 15 to 24 have access to the information, education, including peer education and youth-specific HIV education, and services necessary to develop the life skills required to reduce their vulnerability to HIV infection, in full partnership with young persons, parents, families, educators and health-care providers ... (paragraph 53);
- **By 2003**, develop and/or strengthen strategies, policies and programmes ... to reduce the vulnerability of ... young people by ensuring access of both girls and boys to primary and secondary education, including HIV/AIDS in curricula for adolescents; ensuring safe and secure environments, especially for young girls; expanding good-quality, youth-friendly information and sexual health education and counselling services; strengthening reproductive and sexual health programmes; and involving families and young people in planning, implementing and evaluating HIV/AIDS prevention and care programmes, to the extent possible (paragraph 63).

In the 2006 *Political Declaration on HIV/AIDS*, Heads of State and Government, and representatives of States and Governments renewed their commitment "to addressing the rising rates of HIV infection among young

people” (paragraph 26). But many countries have failed to live up to this commitment. In his 2006 report on progress made in the implementation of the *Declaration of Commitment on HIV/AIDS*, the UN Secretary-General highlighted the following shortfall.

HIV prevention efforts remain notably inadequate for young people, who account for half of all new infections ... Although the *Declaration of Commitment* provided that 90 per cent of young people would be knowledgeable about HIV by 2005, surveys indicate that fewer than 50 per cent of young people are properly educated about HIV.¹⁰⁴

As part of their broader efforts to hold the executive to its HIV-related promises (see the section, Hold the executive to its promises, in Chapter 3), parliamentarians should track whether their governments are fulfilling the promises they made related to young people and, if necessary, demand that their governments live up to these promises.

CHAPTER 12

Reducing vulnerability among other populations at risk

At risk and neglected: four key populations¹⁰⁵

This chapter focuses on four key populations at higher risk: men who have sex with men; people who use drugs; sex workers; and prisoners. In most

The vulnerable must be given priority in the response.

– Declaration of Commitment on HIV/AIDS, 2001 (preface to sections 62–64)

countries, these populations have a higher prevalence of HIV infection than that of the general population because they engage in behaviours that put them at higher risk of becoming infected, and they are among the most marginalized and discriminated-against populations in society.

Punitive approaches to drug use, sex work, and homosexuality fuel stigma and hatred against these populations, pushing them further into hiding and away from services to prevent, treat and mitigate the impact of HIV.¹⁰⁶ At the same time, the resources devoted to HIV prevention, treatment and care for these populations are not proportional to the HIV prevalence, which represents a serious mismanagement of resources and a failure to respect fundamental human rights.

- In many countries, people who use illicit drugs represent the smallest fraction of individuals receiving ART, despite accounting for the majority of people living with HIV. Harsh drug laws effectively criminalize the status of being a drug user, leading many people who use drugs to end up in prison or in a revolving door of ineffective and coercive rehabilitation programmes, rarely receiving the health and social services for drug addiction or HIV prevention and treatment that they desperately need.
- Sex workers, whose conduct also attracts criminal penalties under laws prohibiting prostitution, soliciting, pimping, brothel-keeping and trafficking, often lack access to HIV services due to exploitation within the industry, as well as widespread police abuse. Forcible displacement of sex workers from commercial development areas further interferes with sex workers' access to community-based HIV services. Prejudicial and coercive treatment of sex workers in health facilities deters them from seeking HIV treatment and care. Aggressive efforts to abolish human trafficking often translate into lack of attention or opposition to programmes that focus on the health and human rights of sex workers.
- Men who have sex with men face widespread violence and discrimination around the world, as well as continued criminalization of sodomy in many countries. The stereotype of AIDS as a 'gay disease' continues to reinforce discrimination against gay men and people living with HIV alike, often driving both populations away from mainstream health services. In many jurisdictions, police officers are more likely to ridicule or compound violence against gay men and transgender persons rather than investigating

these crimes properly. Politicians from many countries pander to anti-gay prejudice rather than demonstrating the political will needed to combat HIV among vulnerable groups.

- Prisoners in many countries have little or no access to voluntary HIV testing or treatment. They are often denied access to HIV prevention information and tools, even in places where these are available outside prison. Condoms and sterile needles and syringes are often not provided, despite strong evidence of their effectiveness in preventing HIV without posing a risk to the wider prison population. Segregation of HIV-positive prisoners, denial of medical release, and failure to take effective action against prison rape are among the many human rights abuses that fuel HIV and worsen its impact in prisons throughout the world.

Reflecting the status in society of these populations and the lack of sympathy they attract, parliamentarians have rarely shown leadership and taken action to address their needs. However, both for public health and human rights reasons, leadership and action are sorely needed. The HIV epidemic forces every sector of society, and particularly its leaders, including members of parliament, to take pragmatic action and embrace an approach to HIV that is informed by evidence and respect for the dignity and human rights of all people. If we fail to do so, there will be tragic consequences – not only for members of vulnerable populations, but ultimately for the general population.

The benefits of taking a pragmatic approach are clear. In *countries with low-level and concentrated epidemics*, well-designed and adequately funded HIV prevention programmes among men who have sex with men, people who use drugs, sex workers and prisoners have proven decisive in slowing or even stopping the epidemic in its tracks. But also *countries with generalized epidemics* will be making the most effective use of resources if they place a high priority on HIV programming for these populations, guided by epidemiological surveillance, and developed and implemented with the meaningful involvement of these populations.

Box 46**Vulnerable populations and HIV: What have countries committed to?**

By 2003, in order to complement prevention programmes that address activities which place individuals at risk of HIV infection, such as risky and unsafe sexual behaviour and injecting drug use, have in place in all countries strategies, policies and programmes that identify and begin to address those factors that make individuals particularly vulnerable to HIV infection, including underdevelopment, economic insecurity, poverty, lack of empowerment of women, lack of education, social exclusion, illiteracy, discrimination, lack of information and/or commodities for self-protection, and all types of sexual exploitation of women, girls and boys, including for commercial reasons. Such strategies, policies and programmes should address the gender dimension of the epidemic, specify the action that will be taken to address vulnerability and set targets for achievement (paragraph 62, *Declaration of Commitment on HIV/AIDS*).

By 2003, develop and/or strengthen national strategies, policies and programmes ... to promote and protect the health of those identifiable groups which currently have high or increasing rates of HIV infection or which ... are at greatest risk of and most vulnerable to new infection as indicated by such factors as the local history of the epidemic, poverty, sexual practices, drug-using behaviour, livelihood, institutional location, disrupted social structures and population movements, forced or otherwise (paragraph 64, *Declaration of Commitment on HIV/AIDS*).

In the **2006 Political Declaration on HIV/AIDS**, Heads of State and Government, and representatives of States and Governments renewed their commitment "to intensifying efforts to enact, strengthen or enforce, as appropriate, legislation, regulations and other measures to eliminate all forms of discrimination against, and to ensure the full enjoyment of all human rights and fundamental freedoms, by people living with HIV and **members of vulnerable groups**, in particular to ensure their access to, inter alia, education, inheritance, employment, health care, social and health services, prevention, support and treatment, information and legal protection, while respecting their privacy and confidentiality ..." (paragraph 29).

What do the International Guidelines on HIV/AIDS and Human Rights say?

According to **Guideline 4**, "States should review and reform criminal laws ... to ensure that they are consistent with international human rights obligations and are not misused in the context of HIV/AIDS or targeted against vulnerable groups".

According to **Guideline 8**, "States should ... promote a supportive and enabling environment for ... vulnerable groups ...".

Reducing vulnerability among men who have sex with men

Summary

Why leadership and action to address HIV among men who have sex with men are so important

- In all regions of the world, men who have sex with men are severely affected by HIV, but their needs have been largely ignored and under-funded.
- Many men who have sex with men also have sex with women. Neglecting their prevention needs can seriously affect the course of the HIV epidemic. Vulnerability to HIV infection is dramatically increased where sex between men is stigmatized and criminalized.

What you can do

- Parliamentarians can provide public support for prevention measures for men who have sex with men; support community action of men who have sex with men; remove policy and legal barriers to prevention and care, including repealing laws that criminalize same-sex acts between consenting adults in private, and enacting anti-discrimination legislation to reduce human rights violations based on sexual orientation; and demonstrate public commitment for non-discriminatory treatment of men who have sex with men.

Why are leadership and action to address HIV among men who have sex with men so important?

In all regions of the world, men who have sex with men are severely affected by HIV

Some countries continue to deny the existence of homosexual practices or claim that they are a Western construct or import, despite studies providing evidence that men who have sex with men are found in all countries.¹⁰⁷ Yet these groups are largely invisible in many places.

In some regions of the world, epidemiological information about male-to-male HIV transmission is relatively scarce. This is partly because of the fact that many of the men involved are married to women and are thus regarded as part of the general population, rather than a distinct subpopulation. Crucially, in many parts of the world, men who have sex with men have no separate social identity (unlike self-identified ‘gay’ men) and sex between men is not commonly talked about or acknowledged.

Nevertheless, much research has been carried out in low- and middle-income countries, and the burden of HIV infection in men who have sex with men has become increasingly clear. Sex between men is central to the HIV epidemic in nearly all Latin American countries. But it also has important implications in other regions. In Bangkok, for example, HIV infection levels of 28% have been found in men who have sex with men;¹⁰⁸ in Phnom

Penh, 15%;¹⁰⁹ in Mumbai, 17%.¹¹⁰ In Africa, high rates of HIV among men who have sex with men have been documented in a number of countries, including Kenya¹¹¹ and Senegal.¹¹²

Globally, HIV transmission among men who have sex with men accounts for 5–10% of all HIV infections.¹¹³

Box 47

What does the term 'men who have sex with men' describe?¹¹⁴

The term 'men who have sex with men' describes a social and behavioural phenomenon rather than a specific group of people. It includes not only self-identified gay and bisexual men, but also men who engage in male–male sex and self-identify as heterosexual or who do not self-identify at all, as well as transgendered males.

Many men who have sex with men do not regard themselves as homosexual, and many men who have sex with men also have sex with women. In a study in Beijing, 28% of the men surveyed reported having sex with both men and women during the previous six months.¹¹⁵ A large study, conducted in Andhra Pradesh, found that 42% of men in the sample who have sex with men are married and that 50% had had sexual relations with a woman within the previous three months.¹¹⁶

Complex gender issues, social and legal marginalization and lack of access to HIV information affect how many of these men perceive, or do not perceive, their HIV-related risks. Traditional gender norms of masculinity and femininity contribute strongly to homophobia and the related stigma and discrimination against men who have sex with men and transgendered people.

The needs of men who have sex with men have been largely ignored or under-funded

Even in the many countries where data indicate that men who have sex with men are severely affected by HIV, their needs have been largely ignored or under-funded.

Current indicators suggest that, globally, only 9% of men who have sex with men have access to the HIV prevention and care services they need.¹¹⁷ Many factors contribute to this situation, including denial by society and communities, stigma and discrimination, and human rights abuse.

Homophobia has been identified as one of the primary obstacles to effective HIV responses in the move towards universal access to treatment.

Vulnerability to HIV infection is dramatically increased where sex between men is criminalized

Criminal laws prohibiting specific sexual activity between consenting adults in private – such as adultery, sodomy, fornication or acts 'against the order of nature' or against the social order or morality – severely limit the ability of many men who have sex with men to access HIV prevention information, commodities and treatment and care.¹¹⁸ Faced with legal or

social sanctions, men having sex with men are either excluded from, or exclude themselves from, sexual health and welfare agencies because they fear being identified as homosexual.

Many jurisdictions have repealed these laws because they are ineffective and out of date; more recently and urgently, such laws are being repealed on public health grounds. One such jurisdiction is the Russian Federation, where a law criminalizing homosexuality was repealed in 1992.

However, numerous countries still have these laws. They vary in degrees of severity of punishments, including fines, corporal abuse, and long-term incarceration. Laws in Iran, Nigeria, Pakistan, Saudi Arabia and Sudan may impose the death penalty for sexual offences committed by men who have sex with men. In Jamaica, men having sex with men can be convicted of a crime and sentenced to jail. Same-sex relations between men in Malawi attract a 14-year penal sentence.¹¹⁹

Men who have sex with men are also often targeted for prosecution or harassment through laws that are enacted on the grounds of needing to protect the morality and decency of society. These statutes may take the form of laws against ‘anti-social behaviour’, ‘immoral behaviour’, ‘causing a public scandal’, or ‘loitering’, among others. Police may use these laws to arrest men known to have, or suspected of having, sex with men. Staff of NGOs that try to help men who have sex with men can be targeted through the same statutes or may be charged for abetment of a criminal offence. Laws that prohibit ‘promotion of homosexuality’ have been used to prevent distribution of materials dealing with safer sex and public health issues faced by men who have sex with men. Ultimately, the enforcement of these criminal statutes leads to public humiliations and infringements of other rights of men who have sex with men.

In addition, police authorities in certain countries have been known to go beyond disbanding gatherings of men who have sex with men to include arrest and abuse. In a 2002 survey conducted in Senegal, 13% of men who have sex with men reported being raped by a policeman who used his authority improperly to coerce victims into having sex with him.¹²⁰ A study on rights abuses in Kazakhstan revealed that male and transgender sex workers are regularly raped, beaten and subject to extortion by the police.¹²¹ In these and other examples, police may use laws that discourage homosexual behaviour to justify their discrimination or other offensive acts.

Prevention efforts in some countries seem to be losing ground

In some countries, self-identified homosexual men have taken their place within mainstream society through a process of activism, legal reform and

changes in social attitudes. They have been at the forefront of HIV prevention since the early years of the epidemic. For example, a survey of men who have sex with men in India found that use of peers to distribute and promote condoms resulted in significant increases in condom use.¹²²

Yet some of the success against HIV achieved by men who have sex with men is being eroded. Sexual risk-taking among men who have sex with men is increasing in many countries. The resurgence of risk behaviours has a number of possible explanations. One may be the erroneous belief that, with widespread access to ART now available, AIDS is more or less curable and protected sex is therefore optional. At the same time, public health authorities in most countries are devoting fewer resources to men who have sex with men than epidemiological evidence suggests is necessary. Rising HIV prevalence among this population in many countries confirms that this is a short-sighted public policy.

Box 48

An example of leadership and action: Brazil scales up prevention programmes for men who have sex with men

Brazil has rapidly scaled up prevention programmes for men who have sex with men. Between 1999 and 2003, the number of World Bank-supported HIV prevention projects for Brazilian men who have sex with men increased from 17 to 234.

What parliamentarians can do

Support prevention measures for men who have sex with men

- Provide public support for a range of responses aimed at reducing the risk behaviours and vulnerability to HIV of men who have sex with men that have proven successful in a variety of settings, including:
 - promotion of access to condoms and water-based lubricants;
 - safer-sex campaigns and skills training;
 - peer education among men who have sex with men, along with outreach programmes by volunteers or professional social or health workers;
 - provision of education and outreach to female partners of men who have sex with men;
 - programmes tailored to particular subpopulations, such as prisoners and male sex workers
 - programmes that meet the prevention information and service needs of transgendered persons;
 - development of friendly and supportive health care and social services for men who have sex with men;

- training and sensitization of health-care providers, police and military personnel to avoid discriminating against men who have sex with men;
- access to medical and legal assistance for boys and men who experience sexual coercion or violence.

Support community action of men who have sex with men

- Encourage managers of health systems, governments and donors to support activities aimed at empowering men who have sex with men to participate equally in social and political life, including by:
 - supporting organizations of self-identified gay men, enabling them to promote HIV prevention and care programmes;
 - supporting alliances between epidemiologists, social scientists, politicians, human rights groups, lawyers, clinicians, journalists, organized groups of men who have sex with men, and other civil society organizations;
 - making available safe virtual or physical spaces (e.g. telephone hotlines or drop-in centres) for men who have sex with men to seek information and referrals for care and support.

Remove policy and legal barriers to prevention and care for men who have sex with men

- Repeal laws that criminalize same-sex acts between consenting adults in private.
- Review laws, policies and practices to assess whether they have been used to harass men who have sex with men or to prevent crucial public health information from reaching them, and change them, if necessary.
- Enact anti-discrimination or protective laws to reduce human rights violations based on sexual orientation.

Demonstrate public commitment for non-discriminatory treatment of men who have sex with men

- Demonstrate public commitment by asking governments, national AIDS commissions, community organizations and donors to include men who have sex with men in HIV programming and funding priorities.
- Demand that national AIDS action frameworks include specific prevention, treatment and care plans for men who have sex with men.
- Call for supportive, non-discriminatory treatment of men who have sex with men.

Box 49**Examples of laws and policies that protect individuals from discrimination based on sexual orientation**

South Africa enshrined the protection of individuals from discrimination based on sexual orientation in its Constitution: 2.9 (3) “The state may not unfairly discriminate directly or indirectly against anyone on one or more grounds, including race, gender, sex, pregnancy, marital status, ethnic or social origin, colour, *sexual orientation*, age, disability, religion, conscience, belief, culture, language and birth.” The Constitutional Court of South Africa has enforced this clause in a series of judgements.

On the supranational level, the European Union Council *Directive 2000/78/EC* of 27 November 2000 established a general anti-discrimination framework in employment and occupation, which requires individual national legislation to come into effect in each Member State: (12) “To this end, any direct or indirect discrimination based on religion or belief, disability, age or *sexual orientation* as regards the areas covered by this Directive should be prohibited throughout the Community.”

For additional examples, see: World Bank (2007). *Legal Aspects of HIV/AIDS, A Guide for Policy and Law Reform*: siteresources.worldbank.org/INT/HIVAIDS/Resources/375798-1103037153392/LegalAspectsOfHIVAIDS.pdf.

Reducing vulnerability among people who use drugs**Summary****Why leadership and action to address HIV among people who use drugs are so important**

- Worldwide, injecting drug use is a growing problem. It now accounts for one-third of new infections outside sub-Saharan Africa, yet prevention and treatment are sorely lacking for people who inject drugs. People who use illicit drugs by inhalation or other means are also at risk of HIV.
- There is evidence that harm reduction measures (such as access to sterile injecting equipment and opioid substitution therapy) are feasible, effective as public health measures, cost-effective, and do not lead to increased drug use. The implementation of these measures is not only permissible under the international drug control treaties but is also consistent with (and arguably required by) States’ obligations under the international law of human rights. Nevertheless, in many countries, people who use drugs do not have access to such measures.
- Instead of relying on evidence-informed interventions, many countries take an approach that is strictly or overwhelmingly focused on criminalization and the imposition of harsh penalties. There is increasing evidence from many settings that such an approach can increase the harms associated with problematic drug use rather than helping to address the problem.

What you can do

- Many parliamentarians refrain from speaking out on this controversial issue and shy away from engaging with people who use drugs, focusing instead on issues that will attract widespread support. This makes it all the more important to give priority to representing the needs of people who use drugs and to advocate policies and practices that prevent discrimination, intolerance and human rights violations. In addition, parliamentarians can remove legal barriers to prevention and care.

Why are leadership and action to address HIV among people who use drugs so important?

*Worldwide, injecting drug use is a growing problem*¹²³

- There are approximately 13 million injecting drug users worldwide, of whom 8.8 million live in Eastern Europe and Central, South and South-East Asia.
- There are around 1.4 million injecting drug users in North America and 1 million in Latin America.
- Use of contaminated injecting equipment during drug use is the major route of HIV transmission in Eastern Europe and Central Asia, where it accounts for more than 80% of all HIV cases. It is also the entry point for HIV epidemics in a wide range of countries in the Middle East, North Africa, South and South-East Asia and Latin America.
- Alarming, new epidemics of injecting drug use are being witnessed in sub-Saharan Africa.

Injecting drug use is estimated to account for one-third of new infections outside sub-Saharan Africa, yet prevention and treatment are sorely lacking

- Once HIV enters a community of people who inject drugs, progress of the infection into the rest of the population can be very rapid if appropriate measures are not taken early.
- Yet in spite of the importance of addressing the needs of people who inject drugs, estimates from 94 reporting low- and middle-income countries suggest that only 8% of people who inject drugs receive some type of prevention service.
- Even fewer have access to comprehensive services, including opioid substitution therapy and needle and syringe programmes.
- Injecting drug users also continue to have poor and inequitable access to ART. In Central Asia and Eastern Europe, where nearly 83% of HIV cases are attributed to injecting drug use, former or current injecting drug users only represented 24% of the people on ART at the end of 2004.¹²⁴

HIV spread through injecting drug use can be explosive and early action is critical

- Once HIV enters a population of people who inject drugs, it can spread quickly unless effective action is taken. In many places, infection rates among people who inject drugs have increased from 5% to 50% in one year.

- People who inject drugs often face additional risks of contracting and transmitting HIV, such as via sex work or as a result of incarceration for possession of drugs.
- From people who inject drugs, HIV then spreads more widely through sexual transmission to the general population. What is – or is not done – to contain the spread of HIV among people who inject drugs thus concerns everyone.
- Because HIV rates can increase so rapidly among people who inject drugs, countries are urged to act early and to create the conditions (such as an enabling social and legal environment) necessary for effective action to prevent the spread of HIV, before there is evidence of high rates of infection among people who inject drugs.

Certain other forms of drug use also expose people to the risk of HIV

People who use drugs *by injecting* are at particularly high risk of contracting HIV, but certain other forms of drug use also expose people to the risk of HIV. For example, crack cocaine (a stimulant that is derived from powdered cocaine using a simple conversion process) can increase sexual desire, which may lead to unsafe sex. Unprotected sex is also likely when sex is exchanged for crack. Crack smoking may also be a co-factor in the transmission of HIV because it can cause severe burns or cuts on the mouth and lips, which can serve as a transmission site for HIV or other blood-borne infections during oral sex or when sharing pipes used for smoking crack.¹²⁵

We know what works

Drug use and drug dependence are primarily a health and social issue. Health interventions are more likely than punitive approaches to be successful in addressing the potential harms deriving from drug use, including the risk of HIV infection. In particular, there is evidence that harm reduction measures (such as access to sterile injecting equipment, opioid substitution therapies with methadone and buprenorphine, and community-based outreach) are feasible, effective as public health measures and cost-effective.¹²⁶

Needle and syringe programmes allow people who inject drugs to access clean injecting equipment. These programmes are often controversial and may be illegal under a country's drug laws. In addition, communities may worry that such programmes give citizens the idea that drug use is permissible, that they increase drug use, or that resources are being devoted to unpopular sectors of society. However, such programmes have been very successful in reducing the transmission of HIV. In a review of more than 200 studies,

the World Health Organization (WHO) found that the “HIV infection rate had declined by an average of 18.6% annually in 36 cities with needle and syringe programmes, whereas it had increased by an average of 8.1% annually in 67 cities lacking such programmes”.¹²⁷ Needle and syringe programmes have also proven to be extremely cost-effective. Finally, studies have found no evidence that such programmes increase illicit drug use, increase injecting frequency among those who do use, or recruit new users.

Opioid substitution therapy is another essential part of a comprehensive response to HIV in countries with significant opioid addiction. This form of therapy seeks to reduce or eliminate use of illegal opioids by stabilizing people’s cravings for as long as is necessary to help them avoid previous patterns of substance use and associated harms. Opioid substitution therapy has been recognized by the WHO and many national medical associations as an effective, safe and cost-effective means of managing opioid dependence and as an essential HIV prevention measure. More specifically, the therapy reduces the use of illegal opioids; reduces the risk of transmission of HIV and other blood-borne diseases through sharing drug injection equipment, since it is usually administered orally; reduces costs to the health, law enforcement, and criminal justice systems by helping people who use drugs to avoid lengthy hospital stays, criminal investigations, convictions and imprisonment; and promotes community integration and improved quality of life for people who use drugs and their families. The WHO has included methadone and buprenorphine – both used in opioid substitution therapy as alternatives to heroin or other opium derivatives – in its *Model List of Essential Medicines*.

We know what does not work

In contrast to a pragmatic approach that focuses on providing people with the health interventions they need, there is increasing evidence that criminal prohibitions do not address – and can even worsen – some of the harms associated with problematic drug use. Traditionally, policies on drug use have focussed on reducing supply of, and demand for, drugs – both of which are important elements of policy wherever drug use poses a serious threat to public health. But care must be taken to ensure that the nature and implementation of supply and demand reduction policies do not increase the vulnerability of people who use drugs to HIV infection.¹²⁸ The widespread epidemic of HIV among people who inject illicit drugs has highlighted the limits and problems of an approach that is exclusively or overwhelmingly focused on criminalization and the imposition of harsh penalties.

- In some situations, violations of the human rights of people who use drugs have been demonstrably linked to law enforcement-based approaches to drug use. For example, there are documented cases of illegal police searches, arbitrary arrests, prolonged pre-trial detention, as well as unwarranted use of force, harassment and extortion on the part of police and border guards towards people who use drugs. Other reports document cases of detainees who are interrogated while they are in drug withdrawal and experiencing pain and confusion, or who are denied the right to a lawyer. Such human rights abuses drive people who use drugs further underground, thus preventing a vulnerable population from seeking and using health and social services.¹²⁹
- Registration of people who use drugs, as required in some countries, also creates disincentives to accessing services and, in particular, to seeking treatment for drug dependence.¹³⁰
- Strict law-enforcement practices also reinforce stigma against people who use drugs and may impede access to essential health-care services among people who use drugs. Criminal sanctions may make it difficult for health professionals to reach people who use drugs with essential health information and services; may make people who use drugs afraid to seek health or social services on their own initiative; may make service providers shy away from providing essential education on safer use of drugs or materials for the safer use of drugs (e.g. distributing sterile injection equipment), for fear of being seen to condone or promote drug use; and may foster prejudicial attitudes towards people who use drugs, directing action only towards punishment of the ‘offender’, rather than fostering understanding and assistance.

Legal and social barriers often impede access to essential interventions

Despite the demonstrated effectiveness of needle and syringe programmes and opioid substitution therapy, millions of people around the world who use drugs do not have access to such services because of legal and social barriers.

- While reusing needles is dangerous, some countries have laws in place that hamper access to clean injecting equipment. In some countries, syringes cannot be obtained at a pharmacy without a prescription. Additionally, in many countries, drug paraphernalia laws make possessing syringes for drug use unlawful. The WHO has found that such legislation is a barrier to effective HIV prevention. In fact, there is evidence that restricting access to injecting equipment inadvertently increases the incidence of HIV infection.
- Methadone and other opioid substitutes continue to be classified as illegal in many countries, making the administration of the most effective form of treatment for opioid users impossible.

Beyond their treatment under the law, people who use drugs may be ostracized by their families and communities, and some countries have undertaken public campaigns against drug use and users, including stigmatizing media coverage, public beatings of people who use drugs, and sometimes public executions. Such actions do not have a cause-and-effect relation to HIV rates, per se, but they stigmatize people who use drugs, deterring them from coming forward for help, and hampering prevention programmes.

In short, people who use illegal drugs are often not recognized by law or society as the equal human beings that they are who also have full human rights, including within the legal and health systems.

Harm reduction measures are not only permissible, but required by States' obligations under international law

The spreading HIV epidemic, and the other harms encountered by people who use drugs in unsafe ways or conditions, highlight the fact that governments have good public health reasons to ensure that their domestic legislation and policies on drug control do not contribute to these harms and do not impede health promotion efforts among people who use drugs. However, governments also have legal obligations to act. The implementation of various harm reduction measures is not only permissible under the international drug control treaties, but is also consistent with – and arguably required by – States' obligations under the international law of human rights.

In legislating in the area of controlled drugs and substances, countries must necessarily have regard for their obligations under applicable international law. This includes the UN's three major drug control conventions: the 1961 *Single Convention on Narcotic Drugs*; the 1971 *Convention on Psychotropic Substances*; and the 1988 *United Nations Convention Against Illicit Traffic in Narcotic Drugs and Psychotropic Substances*.

It has sometimes been argued that these conventions make it difficult for States to implement evidence-informed HIV prevention measures for people who use drugs. However, these conventions can be interpreted so as to permit approaches that treat drug use as a health concern. In particular, the conventions may be correctly interpreted to support the implementation of measures such as opioid substitution therapy and needle and syringe programmes. The UN Drug Control Program (UNDCP), located within the UN Office on Drugs and Crime, issued a legal opinion to the International Narcotics Control Board (INCB), concluding that these measures can be seen as consistent with the UN drug control conventions.¹³¹

The conventions also allow States some flexibility in the extent to which they criminalize possession and use of controlled substances.

Importantly, in enacting and implementing domestic legislation and policy in the area of controlled drugs and substances, governments must not only have regard for drug control treaties, but also consider their obligations under international law to respect, protect and fulfil human rights. Under the *Charter of the United Nations*, all Member States have a binding treaty obligation “to take joint and separate action” to achieve the purpose of the UN, including promoting “solutions of international ... health problems” and “universal respect for, and observance of, human rights and fundamental freedoms for all”.¹³² The UN Charter also expressly states that, in the event of a conflict between a country’s obligations under the Charter and their obligations under any other international agreement, their obligations under the former prevail. This means that countries cannot validly implement international drug control treaties in ways that contradict their obligations to solve health problems and respect human rights. At the 1998 UN General Assembly Special Session on Drugs, UN Member States declared that action against drugs requires “an integrated and balanced approach in full conformity with the purposes of the *Charter of the United Nations* and international law, and particularly with full respect for ... all human rights and fundamental freedoms”.¹³³

What parliamentarians can do

Advocate a health approach to drug use and non-discriminatory treatment of people who use drugs

Many parliamentarians refrain from speaking out on this controversial issue and shy away from engaging with people who use drugs, focusing instead on issues that will attract widespread public sympathy. This makes it all the more important to give priority to representing the needs of people who use drugs and to advocate policies and practices that prevent discrimination, intolerance and human rights violations.

- Educate people about the fact that dependence on drugs is primarily a health issue and that over-reliance on criminal law approaches to drug use can lead to rapid spread of HIV not only among people who use drugs, but also the general community.
- Call for supportive, non-discriminatory treatment of people who use drugs and for the removal of stigmatizing and coercive measures that exist in some jurisdictions, such as mandatory registration or forced HIV testing.
- Demonstrate public commitment by asking governments, national AIDS commissions, community organizations and donors to include people who inject drugs in HIV programming and funding priorities.
- Demand that national AIDS action frameworks include specific prevention, treatment and care plans for people who inject drugs.

Box 50

An example of leadership and action: A member of parliament represents the issues and concerns of people who use drugs

I am a Canadian Member of Parliament who has for 10 years represented a federal riding (electoral district) which includes an inner city community with the highest HIV/AIDS rate of drug users in the western world. It is an amazing community and I am proud to represent the issues and concerns of drug users who are most often ignored or criminalized by the political and justice systems.

After being elected in 1997, I learned quickly that death from drug overdoses was a preventable health crisis in my community, too long ignored, with devastating consequences for drug users and the community as a whole.

I have worked closely with drug users and grass-roots organizations to bring about public policy changes to uphold the human rights of users, to ensure access to health care, harm reduction programmes, housing, and social support.

This includes actively working for the establishment of a safe injection facility, heroin prescription trials, street-accessed services, needle exchanges, and opposing the harmful impacts of law enforcement tactics against drug users. Responding to injection drug use as a public health issue is critical to saving lives and improving the health and safety of the community overall.

Working closely with users, and making sure they are heard politically, is most important to this work.

I have learned that traditional measures of criminalization and isolation are harmful and a waste of public resources, not to mention an infringement on human rights and civil liberties of individual citizens. I have also learned that political leadership is necessary and important to break down stereotypes and barriers to assist drug users improve their quality of life and health.

My work involves lobbying the government, advocating public policy changes, participating on parliamentary committees, and staying in close contact with key organizations to raise the visibility and effectiveness of these issues.

I continue to find strong public support for this work, as more people understand that the so-called war on drugs is a failed and enormously expensive strategy that does not work.

I work to bring about consensus and understanding of the experience of drug users and consider it critical to make it part of the political process, including access to voting, peer-run programmes, and making sure drug users themselves are heard and represented.

Since winning my seat in 1997, I have been re-elected three times and do not see my work as contrary to broad public support. Indeed, many people are supportive and enthusiastic when elected representatives are willing to speak the truth about failed drug policies and in favour of a comprehensive public health approach that affirms and strengthens people's rights and dignity.

– Libby Davies, Member of Parliament, Vancouver East, House Leader for the New Democratic Party, Canada, 2007

Support prevention and treatment, care and support measures for people who use drugs

- Provide public support for a range of proven responses aimed at reducing the risk behaviours and vulnerability to HIV of people who use drugs:¹³⁴
 - access to needle and syringe programmes;
 - access to quality, non-coercive drug treatment programmes, especially opioid substitution therapy with methadone or buprenorphine;
 - training of health providers to increase familiarity and effective work with people who use drugs;
 - training law enforcement personnel to reduce and eliminate harassment at prevention and treatment sites serving people who use drugs (since fear of arrest among those who use drugs will undermine the success of the programme);
 - rapidly scaled-up and equal access to ART and care services for people who use drugs;
 - peer education among people who use drugs, along with outreach programmes by volunteers or professional social or health workers;
 - provision of education and outreach to sexual partners of people who use drugs;
 - access to legal assistance for people who use drugs and experience discrimination or violence.

Support community action among people who use drugs

- Consult with people who use drugs, support them in claiming their rights to prevention and care, and actively involve them in any initiatives related to AIDS and drug use.
- Encourage managers of health systems, governments and donors to support activities aimed at greater and more meaningful involvement of people who use drugs in the decisions concerning their lives, including by supporting organizations of people who use drugs, enabling them to promote HIV prevention and care programmes and advocating respect for the dignity and human rights of people who use drugs.

Advocate balanced budget allocations

In many countries, significant resources are spent on law enforcement, but very little money is spent on scientifically sound measures to prevent drug dependence, the expansion of humane and human rights-respecting treatment of drug dependence, and evidence-based HIV prevention measures among people who use drugs, such as needle and syringe programmes.

- Advocate balanced spending for all elements of the response to HIV and drug use, ensuring that effective approaches to reducing the spread of HIV through injecting drug use are adequately funded.

Remove legal barriers to prevention and care, and enact anti-discrimination legislation

- Remove legal barriers to prevention and care, such as laws and policies that prevent the provision of sterile injecting equipment or access to opioid substitution therapy.
 - ***Ensure easy access to sterile needles and syringes.*** Countries should decriminalize the purchase and possession of needles and syringes and related material. In order for needle and syringe programmes to be effective, laws need to ensure that all of those involved are protected from arrest, including workers at needle and syringe programmes, pharmacists, medical practitioners and users. Laws that criminalize ‘facilitation’ or ‘incitement’ of drug use should exclude all aspects of needle and syringe programmes. Education and provision of information about the exchange must also be lawful. Users must not be made criminally liable for possession of syringes or of trace amounts of drugs found in used syringes that are going to be turned in. Records of needle and syringe programmes as well as programme workers must be protected from subpoena by police and being used as evidence in drug-related legal proceedings. If people who inject drugs fear that using a programme could lead to their arrest, the programme will not be successful. Police should be trained to ensure that they do not harass users of needle and syringe programmes or use the sites to gather information for criminal proceedings.
 - ***Ensure easy access to opioid substitution therapy.*** This can be done by authorizing substitution programmes within more general legislation for illicit drug regulation or by passing legislation or enacting policies that specifically authorize substitution programmes. Within such legislation or policy, it is important to explicitly state the need for admission to substitution programmes to be as open as possible. Since many people who use opioids come to substitution programmes at a moment of crisis, the ready availability of programmes is crucial to staying off a worse crisis or to “tak[ing] advantage of the motivation created by ... crises”.¹³⁵ Substitution treatment should be available without discrimination based on age, sex, economic status, social circumstances or other similar criteria, including HIV status.
- Enact anti-discrimination or protective laws to reduce human rights violations based on drug dependence.

Box 51**Key resources: A model law on drug use and HIV**

The Canadian HIV/AIDS Legal Network has drafted a *Model Law on Drug Use and HIV/AIDS*, available in English and Russian. The model law resource is a detailed framework of legal provisions and accompanying commentary. It is designed to inform and assist policy-makers and parliamentarians as they approach the task of reforming or making laws to meet the legal challenges posed by the HIV epidemic among people who use drugs. It is designed to be adaptable to the needs of a wide number of jurisdictions – for low- and middle-income countries where legislative drafting resources may be scarce. It consists of eight modules, addressing the following issues: criminal law; treatment for drug dependence; needle and syringe programmes; supervised drug consumption facilities; prisons; outreach and information; stigma and discrimination; and heroin prescription programmes. Taken together, the model statutory provisions in all eight modules would form a model law addressing HIV and drug use.

For more information and a copy of the model legislation, see:

www.aidslaw.ca/publications/publicationsdocEN.php?ref=620

Box 52**An example of best practice: Viet Nam's Law on the Prevention and Control of HIV/AIDS**

Adopted in 2006, this law explicitly calls for the implementation of harm reduction measures (Art. 21), which, according to the definition (Art. 2.15), include “communication and mobilization, promotion of the use of condoms and clean needles and syringes, treatment of opioid addiction by substitution, and other harm reduction measures to support safe behaviors to prevent HIV infection and transmission”.

Other examples of laws and policies

In the 1990s, Ukraine realized the need to reform its law to allow for harm reduction approaches. The government established a National AIDS Committee composed of experts and studied the legislation of other countries to determine best practices. In 1998, the law was amended to allow for needle and syringe programmes and to abolish mandatory HIV testing of people who inject drugs.

In July 1992, the state of Connecticut, in the United States of America, passed a law permitting the purchase and possession of up to 10 syringes without a prescription and made parallel changes in its paraphernalia law. Following the legislative changes, the number of syringes sold in pharmacies increased, and self-reported needle-sharing declined, as did the incidence and prevalence of HIV.

As pharmacies are often closed at night, some countries have experimented with the installation of syringe-vending machines, to make needles available at all times. In New South Wales, Australia, the *Needle and Syringe Program Policy and Guidelines* provide for multiple points of access to clean needles, including vending machines, pharmacies, and centres designed to provide needles along with other health and drug-cessation services.

For additional examples, see: World Bank (2007). *Legal Aspects of HIV/AIDS, A Guide for Policy and Law*

Reform: siteresources.worldbank.org/INTHIVAIDS/Resources/375798-1103037153392/LegalAspectsOfHIVAIDS.pdf.

Reducing vulnerability among sex workers

Summary

Why leadership and action to address HIV among sex workers are so important

- It is estimated that, in many countries, a high proportion of new HIV infections are contracted during paid-for sex.
- There is substantial evidence that HIV prevention programmes for sex workers and their clients are effective. There is also evidence that when sex workers do not live in constant fear of the police and violent clients, when they work in safe conditions, and when they are empowered to control their working environment, their vulnerability to HIV is considerably reduced. Nevertheless, less than a third of sex workers receive adequate HIV prevention services, and even fewer receive appropriate treatment, care and support. Most often, sex workers are not consulted in policy and programme decisions related to their work, even though sex workers in many countries have shown themselves to be very effective in organizing themselves and managing challenging public health programmes.
- In many countries, sex work itself is legal, but criminal law makes many activities related to sex work illegal. This reinforces the stigma associated with sex work and pushes sex workers to the margins of society.
- Although countries may criminalize sex work, sex workers have the same human rights as everyone else, and governments have a responsibility to reach sex workers and their clients with the full range of HIV-related information, commodities and services. Ways must be found to empower sex workers to use these services and to actively participate in the design and provision of the health services they need.

What you can do

- Among many other things, parliamentarians can: (1) speak out against all forms of violence directed against sex workers and highlight the fact that sex workers have the same human rights as any other person; (2) support effective, evidence-informed programmes for sex workers; and (3) review and, if necessary, reform legal frameworks with the aim of removing all barriers to prevention, treatment, care and support, and to respect for the human rights of sex workers.

Background

While it is not possible to accurately count the number of people selling sex, it is estimated that sex workers may number in the tens of millions worldwide – and their clients in the hundreds of millions.¹³⁶ Sex workers can be of all ages, but many are young. The great majority are female, but many men and transgender persons also engage in sex work, and their clients (for both male and female sex workers) are mostly male. In a number of countries, a high percentage of sex workers are migrants.

Sex workers operate in a variety of different environments, ranging from highly organized brothels and massage parlours, to the street, markets, vehicles, cinemas, bars, hotels and homes. Each location carries with it its own degree of risk and vulnerability in terms of stigma, discrimination and the potential for violence, as well as the obvious danger of HIV infection and other STIs.

Why are leadership and action to address HIV among sex workers so important?

HIV prevalence is high among sex workers in many countries

In many countries and regions, a significant number of new HIV infections are contracted during paid-for sex, and a relatively high HIV prevalence has been found among sex workers and their clients. In China, for example, it is estimated that sex workers and their clients account for just under 20% of the total number of people living with HIV.¹³⁷ A study in St Petersburg, Russian Federation, found that 33% of sex workers under 19 years of age tested HIV-positive.¹³⁸ In major urban areas of sub-Saharan Africa, various studies have recorded HIV infection among female sex workers at levels as high as 73% in Ethiopia.¹³⁹ These data underscore the need for HIV prevention and treatment, care and support efforts to be scaled up among sex workers, even in countries with generalized epidemics.

Sex work and injecting drug use are often linked

In many parts of the world, sex work and injecting drug use are intricately linked: people who are dependent on drugs resort to sex work in order to purchase drugs and avoid the pain of physical withdrawal from drugs, while sex workers turn to injecting drugs to escape the pressures of their work. Sex workers who also inject drugs are at further risk; the combination of their work and drug-taking puts them beyond the protection of the law, making them particularly vulnerable to exploitation and abuse, such as sexual violence and harm, and leaving them disempowered in negotiating condom use.

High rates of HIV and STIs have been found among sex workers in countries with large populations of people who inject drugs. In China, Indonesia, Kazakhstan, Ukraine, Uzbekistan and Viet Nam, the large overlap between injecting drug use and sex work is linked to growing HIV epidemics.¹⁴⁰

Many sex workers are young and lack information about HIV

- Most women and men enter sex work in their teens or early 20s.
- Many sex workers lack information about HIV and about services that might help protect them.
- Sex workers are frequently less likely than the general population to access public health services, and may not know about, or be able to afford, treatment for STIs, which can increase physiological vulnerability to HIV.

- The purchase of sexual services from children is always a form of child abuse, which constitutes a violation of the human rights of the child, and should be prosecuted.

Insufficient attention is paid to clients of sex workers

- The majority of HIV interventions that address sex work are aimed at sex workers themselves, with insufficient attention paid to their clients or the contexts in which they work.
- In many countries, the fact that there is consistent demand for sex work is often ignored by government policies, which focus solely on repressing or regulating supply. The prevalence of commercial sex varies greatly. For example, a general population study in 24 Peruvian cities found that 44% of men aged 18–29 years said they paid for sex in 2002.¹⁴¹ In some Asian countries, 15% of men in the general population and 44% of men in mobile, high-risk populations (e.g. long-distance truckers and men who work in mines or forests far from home) reported buying sex during 2004.¹⁴²

HIV programmes for sex workers can be effective – but such programmes are rarely supported

- There is substantial evidence that HIV prevention, treatment, care and support programmes for sex workers (particularly if led by sex workers themselves) are effective and that sex workers can be strong leaders in such programmes.
- There is also evidence that when sex workers do not live in fear of the police and of violent clients, when they work in safe conditions, and when they are empowered to control their working environment, their vulnerability to HIV is reduced.
- Nevertheless, less than a third of sex workers receive adequate HIV prevention services.¹⁴³ Even fewer receive appropriate treatment, care and support. Most often, sex workers are not consulted (or not consulted meaningfully) on policy and programme decisions related to their work, even though sex workers have shown themselves in many countries to be very effective in organizing themselves and managing challenging public health programmes.
- Relatively few donors have provided sustained funding for human rights-based programmes designed and implemented by sex workers.¹⁴⁴

Box 53**Programmes for sex workers: Best practices**

Many of the programmes that have been highlighted as ‘best practices’ embody human rights-based programming that has empowered sex workers to protect themselves from HIV and to be effective HIV educators in their communities. In some cases, empowerment of sex workers and protection and promotion of their rights have gone well beyond the domain of HIV and led to positive changes in the status of sex workers in the community. Best practice examples include the following.

- The Sonagachi project, whereby activities that began as an HIV prevention project became an important social movement for women’s rights and sex workers’ rights. Reliance on sex workers’ own knowledge and professionalism has been one of the project’s hallmarks. The project is also renowned for its well demonstrated and sustained reductions in HIV incidence among sex workers and their clients. The programme has numerous components, including actions designed to help sex workers protect themselves from STIs, to develop safer workplaces and neighbourhoods and educate their communities about the importance of sex workers’ rights, to train police, and to ensure access to a full range of basic services. According to UNAIDS, the project has “demonstrated the great value of gradually placing the control of a community-based health intervention into the hands of the community”.
- A programme run by the *Asociación de Mujeres por el Bienestar y Asistencia Reciproca* (AMBAR) in Caracas, Venezuela, in which sex workers were trainers of other sex workers and community members on human rights, self-esteem, and sexual and reproductive health. Partnerships with legal and human rights organizations enabled cases to be brought to court, based on complaints by sex workers of a range of abuses. Some 25 000 women sex workers became part of the work, with very few reports of HIV infection among them in the first five years of the project. Empowerment of sex workers resulted in dramatic decreases in police harassment.
- **For additional examples, see: (1) UNAIDS. *Innovative approaches to HIV prevention: selected case studies* (UNAIDS Best Practice Collection). Geneva, 2000; (2) UNAIDS. *HIV and sexually transmitted infection prevention among sex workers in Eastern Europe and Central Asia* (UNAIDS Best Practice Collection). Geneva, May 2006; (3) UNAIDS. *Female sex worker HIV prevention projects: Lessons learnt from Papua New Guinea, India and Bangladesh* (UNAIDS Case Study). Geneva, November 2000.**

Criminalizing sex workers increases risks and harms

- In many countries, sex work itself is legal, but criminal law makes many activities related to sex work illegal by outlawing activities such as public solicitation for the sale of sexual services, living off the earnings of a sex worker, or limiting the use of residences for sex work through ‘bawdy house’ provisions. Laws and policies often give the police broad latitude to arrest sex workers (with possession of condoms often considered as ‘proof of prostitution’), as well as to displace sex workers from safer or usual workplaces. Laws unrelated to sex work (such as laws on vagrancy and public

nuisance) may also be applied in discriminatory ways such that sex workers are arrested and detained more frequently than other persons. In many countries, sex workers face very high risk of rape and other abuse, mandatory HIV testing and interruption of ART when they are in the custody of the State.

- This criminalization reinforces the stigma associated with sex work and pushes sex workers to the margins of society. It does so by:¹⁴⁵
 - reinforcing the attitude that sex workers ‘deserve what they get’ when they are beaten up, raped or murdered;
 - making sex work part of an illegal market, thereby bringing together people involved in sex work and other illegal activities, such as the drug scene;
 - creating an environment in which brutal forms of exploitation of sex workers can take place;
 - putting pressure on sex workers to work more in order to pay off fines if they are charged and convicted;
 - making it more difficult for sex workers to get other sorts of work because they have a criminal record.
- Criminalization of sex work also creates a relationship of conflict between sex workers and police. Police may not take sex workers seriously when they report crimes, because of what the sex workers do for a living. Because of this and because they fear arrest, sex workers often do not or cannot turn to the police for help if they need it.
- Systematic police violence and harassment against women, men and transgender persons in sex work (including shocking levels of rape by the police) have been documented in many settings.¹⁴⁶

Sex workers have the same human rights as everyone else

- Although countries may criminalize sex work and thereby subject the act of buying or selling sex for money to criminal sanction, sex workers have the same human rights as everyone else – particularly the right to work, education, information, and the highest attainable standard of health and freedom from discrimination and violence, including sexual violence.
- Governments have a responsibility to protect these rights and, in the context of the HIV epidemic, to reach sex workers and their clients with the full panoply of HIV-related information, commodities and services. Ways must be found to empower sex workers to use HIV services and to actively participate in the design and provision of the health services they need.

Box 54**A distinct policy issue: Trafficking**

Although there are no reliable statistics on this, it is believed that a significant number of women and girls are trafficked into sex work with the promise of a better life for themselves and their families. The figures on the proportion of people trafficked into sex work and those people entering sex work of their own volition, regardless of the reason for doing so, are often disputed and result in significantly different political, legal and policy approaches and outcomes. Clearly, all countries must enact measures to end trafficking (a human rights violation), and parliamentarians can do much to promote the political and legislative climate required for the successful development and implementation of anti-trafficking initiatives. At the same time, it is important not to conflate and confound trafficking and sex work, which are distinct policy issues. In the context of the AIDS epidemic, the provision of access to HIV prevention, treatment, care and support for all sex workers is urgently required.

What parliamentarians can do***Demonstrate public commitment to addressing HIV among sex workers***

- Speak out about the need to provide all sex workers with access to effective HIV prevention, treatment, care and support.
- Speak out against all forms of violence towards sex workers and highlight the fact that sex workers have the same human rights as any other person.
- Speak out against all forms of exploitation and victimization of sex workers, but acknowledge the fact that sex work that does not involve victimization also requires leadership and action.
- Acknowledge the fact that addressing the impact of criminalization and police abuse is a fundamental element of HIV programming for sex workers.
- Ask governments, national AIDS commissions, community organizations and donors to include sex workers in HIV programming and funding priorities.
- Recommend that funds be allocated to programmes that have, as their central elements, HIV prevention, access to treatment, care and support, as well as the protection, promotion and fulfilment of human rights.
- Demand that national HIV action frameworks address the human rights of sex workers and include specific prevention, treatment and care plans for sex workers.

Support effective, evidence-informed programmes for sex workers

- Voice public support for the urgent scale-up of comprehensive, accessible and user-friendly HIV programmes for sex workers. Programmes that have

proven to be successful typically use a mix of strategies and take into account factors such as whether sex workers are brothel-based, if they work in one area or are mobile, and the legal status of sex work. Effective strategies include:¹⁴⁷

- promotion of safer sexual behaviour among sex workers, their partners and clients (e.g. promotion of condom use and negotiation skills), and of sex worker solidarity and local organization;
 - provision of free, accessible services to prevent and treat STIs, which are often co-factors in HIV transmission both to and from sex workers;
 - easy access to prevention commodities, such as male and female condoms and water-based lubricant;
 - access to sexual and reproductive health services, including access to prevention of mother-to-child transmission;
 - peer education and outreach work, including health, social and legal services;
 - access to voluntary HIV counselling and testing as well as to treatment, care and support for sex workers living with HIV;
 - policy and law reform, accompanied by education and training to ensure that those in authority, such as police and public health staff, respect and protect sex workers' human rights.
- Demand that the immediate implementation of such programmes be accompanied by broader, longer-term efforts to address the structural determinants and vulnerabilities that often contribute to entry into sex work. This includes addressing poverty and gender inequality, promoting education for all, promoting employment growth, and addressing the needs of refugees, internally displaced persons, economic migrants and asylum seekers – for many of whom, in the absence of alternative economic options, sex work becomes a means of survival. It should also include economic development programmes that can assist sex workers or potential workers by giving them additional sources of income, so that they are in a better position to choose safer sex, improve opportunities, and/or have fewer clients. Well-crafted alternative income-generation schemes could also help sex workers to leave sex work. These programmes should always be voluntary, and sex workers should participate in their design and management. Moreover, sex workers should enjoy access, without discrimination, to educational and skill-building programmes, without regard to whether they are committed to exiting sex work. In contrast, so-called 'rescue or rehabilitation' programmes may have the effect of driving sex workers underground and making them harder to reach with comprehensive HIV prevention and treatment services.¹⁴⁸

- Demand that sex workers be actively involved in all phases of any programmes – from development to evaluation.

Review and, if necessary, reform legal frameworks

In addition to the *International Guidelines on HIV/AIDS and Human Rights* (see Box 55), many studies and publications have underscored the need for better legal frameworks.¹⁴⁹

- Review criminal legislation in the area of sex work (as well as other laws and policies, including municipal by-laws, that have an impact on sex work), with the aim of removing all barriers to HIV prevention, treatment, care and support for sex workers, as well as to the respect of their human rights.
- Legally regulate occupational health and safety conditions to protect sex workers and their clients; by recognizing the industry through regulation, some of the stigma associated with sex work will be removed.¹⁵⁰ This makes access by health educators with targeted programmes easier, and alleviates the fear of public identification, which, ironically, makes it more difficult to leave the profession. In improving working conditions, a culture of safer sex can be promoted in the industry and responsible behaviour by workers, clients and management can be encouraged. Features of legislation that have successfully regulated the sex industry in some jurisdictions include the following.¹⁵¹
 - Controls on owners/operators should not be too onerous, otherwise a second, illegal sex industry may be created that is inaccessible to health educators.
 - Individual identification or mandatory HIV testing of workers should be prohibited.
 - Managers or clients should be prohibited from requiring unsafe sex and there should be specific regulation of working conditions (e.g. Codes of Practice) requiring management to supply free condoms and sexual health educational material.
- Ensure that all forms of exploitation and victimization are subject to criminal penalties.
- Ensure that policy and law reform is accompanied by education and training of police and public health staff about the need to respect and protect sex workers' human rights. In addition, the enforcement of laws against police officers who commit violence against sex workers is essential.

Box 55

What do the *International Guidelines on HIV/AIDS and Human Rights* say about laws related to sex work?

With regard to adult sex work that involves no victimization, criminal law should be reviewed with the aim of decriminalizing, then legally regulating, occupational health and safety conditions to protect sex workers and their clients, including support for safe sex during sex work. Criminal law should not impede provision of HIV prevention and care services to sex workers and their clients (paragraph 21(c)).

Box 56

An example of law and policy in the context of sex work

In 2003, New Zealand decriminalized sex work in its *Prostitution Reform Act*. The Act permits and regulates sex work, but prohibits sex work by those younger than 18 years of age. The Act requires that all reasonable steps be taken to use an appropriate barrier (condom) if the act engaged in is likely to transmit infection. The Act also mandates that sex workers be represented in national-level policy decision-making related to sex work. Given the legalized status of sex work, the New Zealand Department of Labour published information useful to protecting the health of sex workers: *A Guide to Occupational Health and Safety in the New Zealand Sex Industry*. <http://www.osh.govt.nz/order/catalogue/pdf/sexindustry.pdf>

For additional examples, see: World Bank (2007). *Legal Aspects of HIV/AIDS, A Guide for Policy and Law Reform*: siteresources.worldbank.org/INT/HIVAIDS/Resources/375798-1103037153392/LegalAspectsOfHIVAIDS.pdf.

Reducing vulnerability among prisoners

Summary

Why leadership and action to address HIV among prisoners are so important

- Rates of HIV infection in prison settings tend to be higher than in the community outside prisons, and serious outbreaks of HIV infection have occurred in prisons.
- Governments urgently need to adopt or expand programmes for preventing HIV transmission in prisons. Such programmes should include all the measures against HIV transmission that are carried out in the community outside prisons. Governments also have a responsibility to provide prisoners with treatment, care and support equivalent to that available to other members of the community.
- In the medium- and longer-term, it will also be essential to take action to improve prison conditions and reduce overcrowding.
- In most countries, prison health standards and prison conditions suffer because of a lack of political and public interest in the well-being of prisoners.

What you can do

- Parliamentarians have a crucial role to play in facilitating effective action on AIDS in prisons. In particular, they can: (1) advocate the introduction of comprehensive prevention measures in prisons, and the provision of health services in prisons

equivalent to those in the community; (2) reform laws and policies to reform the prison system and reduce prison populations – by, among other things, reducing pre-trial detention and developing alternatives to imprisonment.

Why are leadership and action to address HIV in prisons so important?

The risk of HIV infection in prison is high

In many countries, groups of people who are at high risk of contracting HIV (including people who inject drugs, sex workers and, generally, the poor and marginalized) are over-represented in prison. As a result, the percentage of people living with HIV in prisons is often much higher than in the community.

Prisoners shall have access to the health services available in the country without discrimination on the grounds of their legal situation.

– United Nations Basic Principles for the Treatment of Prisoners (Principle 9)

- Inside prison, people may use drugs and have sex, with reduced access to the prevention measures (such as condoms and sterile injecting equipment) and health education that are available to people outside prison.
- Unsafe sexual behaviour is widespread, with prisoners having sex (forced or consensual) with each other and, at times, with prison staff.
- Illicit drug use (including injecting drug use) is widespread in prisons in most countries. Even countries with the greatest financial resources have not been able to eradicate drug use in prisons. In addition, some of the measures introduced to deter drug use can increase, rather than reduce, the risk of HIV infection.
- Additional risk factors include the sharing or reuse of tattooing equipment, the sharing of razors for shaving, and the improper sterilization or reuse of medical or dental instruments.
- Factors related to the prison infrastructure and prison management contribute to HIV vulnerability indirectly. They include overcrowding, violence, gang activities, lack of protection for weak or young prisoners, prison staff that lack training or may be corrupt, and poor medical and social services.
- Serious outbreaks of HIV infection have occurred in prisons in a number of countries.

Effective interventions can significantly reduce the risk of infection

Governments should urgently adopt or expand programmes for preventing HIV transmission in prisons. Such programmes should include all the measures against HIV transmission that are carried out in the community outside prisons, including:

- HIV education;
- voluntary HIV testing and counselling;
- condom provision and prevention of rape, sexual violence and coercion;
- provision of sterile injecting equipment to people who inject drugs;
- drug-dependence treatment, particularly opioid substitution treatment;
- measures that reduce the demand for, and supply of, drugs in prisons;
- programmes for the detection and treatment of STIs.

All these interventions help reduce the risk of HIV transmission in prisons. They have been shown to have no unintended negative consequences. The available scientific evidence suggests that they can be reliably expanded from pilot projects to nationwide programmes.

Prison health is public health

Ultimately, since most prisoners leave prison to return to their community, implementing these interventions will benefit not only prisoners and prison staff, but also society in general.

Mandatory HIV testing and segregation are counterproductive

In contrast to the interventions mentioned above, mandatory HIV testing and segregation of HIV-positive prisoners are costly, inefficient, and can have negative health consequences for segregated prisoners.¹⁵² Separate housing of HIV-positive prisoners does not reduce the spread of other sexually transmitted, opportunistic and blood-borne infections such as hepatitis C. Such arrangements raise concerns about disclosure of prisoners' HIV status and access to prison programmes, and do not prevent transmission by prisoners who are unaware that they are infected or by HIV-positive prison staff. Segregation might also increase the risk of TB outbreaks. Such outbreaks, resulting from the implementation of segregated housing, have been documented in California and South Carolina, in the United States of America.¹⁵³ In particular, in a prison in South Carolina, segregating HIV-positive prisoners contributed to a TB outbreak in which 71% of prisoners residing in the same housing area either had new TB skin-test conversion or developed TB disease. Thirty-one prisoners, and one medical student in the community's hospital, subsequently developed active TB.

Therefore, HIV testing in prison should always be voluntary and confidential, and HIV-positive prisoners should not be segregated.

Scaling up access to treatment and care in prisons is fundamental to achieving universal access

In addition to providing comprehensive prevention programmes, governments have a responsibility to provide prisoners with care and treatment equivalent to that available to other members of the community.¹⁵⁴ The right to medical care in prisons includes the right to ART.

As ART is increasingly becoming available in low- and middle-income countries, and as countries are moving towards the goal of universal access to treatment, it will be critical to ensure that ART also becomes available to all prisoners who need it. Ensuring continuity of care from the community to the prison and back to the community, as well as continuity of care within the prison system, is a fundamental component of successful treatment scale-up efforts. The following actions would facilitate this.

- Prison departments should have a place within the national AIDS coordinating committees, and prison issues need to be part of the agreed AIDS action framework and country-level monitoring and evaluation system.
- Prison departments need to be involved in all aspects of treatment scale-up.
- The ministry responsible for health and the ministry responsible for the prison system should collaborate closely, recognizing that prison health is public health.
- Policies or guidelines should be developed, specifying that people with HIV are allowed to keep their medication upon them, or are to be provided with their medication, upon arrest and incarceration, and when they are transferred within the system or to court hearings.

In the longer term, transferring control of prison health to public health authorities could have a positive impact on HIV care in prisons – at least in countries with a well functioning public health service. Experience in a range of prison systems has shown that health care in prisons can be delivered more effectively by public health authorities.¹⁵⁵

Special attention should be given to women prisoners, who require information and services specifically designed for their needs.

Criminal justice and prison reform are also needed

Much can be done to address the problems linked to HIV in prisons by taking action in the areas outlined above. In the medium term, however, it will be essential to take action to improve prison conditions and reduce overcrowding – by, among other things, reducing the time people spend in pre-trial detention and developing alternatives for imprisonment.

In the context of HIV, substandard living conditions can increase the risk of HIV transmission among prisoners by promoting and encouraging drug use in response to boredom or stress, and by enabling prison violence, fighting, bullying, sexual coercion, and rape. Substandard prison conditions can also have a negative impact on the health of prisoners living with HIV, by increasing their exposure to infectious diseases such as TB and hepatitis; housing them in unhygienic and unsanitary environments; by limiting access to open air and to educational, social or work activities; and by failing to provide them with access to proper health care, diet, nutrition, clean drinking water, and basic hygiene.

Box 57

Key resources on responding to HIV in prisons

- For the most comprehensive review of the evidence of the effectiveness of interventions to address HIV in prisons, see: WHO/UNODC/UNAIDS (2007). *Interventions to address HIV in prisons. Evidence for action technical papers*. Geneva. Available via <http://www.who.int/hiv/idu/en/index.html>.
- For a discussion of principles that should guide the response to HIV in prisons, and many recommendations, see: UNODC/WHO/UNAIDS (2006). *HIV/AIDS prevention, care, treatment, and support in prison settings: a framework for an effective national response*. Vienna. Available at www.unodc.org/pdf/HIV-AIDS_prisons_July06.pdf.
- For guidance on what alternatives to imprisonment countries should provide, see: UNODC (2007). *Handbook of basic principles and promising practices on alternatives to imprisonment*. Vienna. Available at www.unodc.org/pdf/criminal_justice/07-80478_ebook.pdf.

What parliamentarians can do

Parliamentarians have a crucial role to play in facilitating effective action on HIV in prisons. Many of the necessary steps will not be possible without action by parliamentarians.

The prison service is a public service, meeting some fundamental needs in society, such as the need to feel safe and to feel that crime is sufficiently punished and the appropriate reparations made. As with all public services, the extent and the quality of provision are a political matter. **Political support for effective action on HIV in prisons should be based on the principle that good prison health is essential to good public health.**

Provide political leadership on HIV in prisons

In most countries, prison health standards and prison conditions suffer because of a lack of political and public interest in the well-being of

prisoners. Taking action to address the broad concerns raised by HIV in prisons, and enabling prison authorities to implement effective policies, requires the political commitment to publicly identify prison health, improved prison conditions, and HIV as issues demanding government action.

Undertake legislative and policy reform

Legislation, prison policy and prison rules need to promote the aforementioned effective responses to HIV in prisons. The extent to which new legislation or policy is needed will vary from jurisdiction to jurisdiction. In some countries, for example, legislation to explicitly authorize HIV prevention measures in prisons will be necessary, while, in others, a simple guideline issued by the head of the prison system will be enough. In all countries, however, a comprehensive review of all laws, policies and rules that affect the ability of prison systems to deal effectively with HIV should be undertaken.

The review of laws should be carried out in parallel with the formulation of an HIV prison policy. Examples of such policies include the ***National HIV/AIDS Policy in Malawi***, whereby the Malawian Government committed to taking the following measures.

- Ensure that prisoners are not subjected to mandatory testing, quarantine, segregation or isolation on the basis of HIV or AIDS status.
- Ensure that prisoners (and prison staff) have access to HIV-related prevention, information, education, voluntary counselling and testing, the means of prevention (including condoms), treatment (including ART), care and support.
- Ensure that prison authorities take all necessary measures, including adequate staffing, effective surveillance, and appropriate disciplinary measures, to protect prisoners from rape, sexual violence and coercion by fellow prisoners and by wardens. Juveniles shall be segregated from adult prisoners to protect them from abuse.
- Ensure that prisoners who have been victims of rape or sexual violence have access to post-exposure prophylaxis, as well as effective complaint mechanisms and procedures, and the option to request separation from other prisoners for their own protection.

Another example is the ***Indonesian National Strategy for HIV/AIDS Control in Prisons*** – the first national strategy of its kind in Asia. Launched in 2005, it has resulted in education as well as provision of condoms, bleach, methadone and ART for prisoners.¹⁵⁶

Box 58 Model legislation on HIV in prisons

Model legislation addressing the HIV epidemic among people who use drugs has been developed by the Canadian HIV/AIDS Legal Network, primarily for the use in low- and middle-income countries. This legislation contains a section on prisons.

For more information and the text of the model legislation, see

<http://www.aidslaw.ca/publications/publicationsdocEN.php?ref=587>.

Advocate increased funding for prisons

Prison systems in many countries do not have the financial resources they need in order to improve prison conditions and provide comprehensive HIV prevention, treatment, care and support. Governments do not usually accord prisons a high priority. In a world with HIV, more than ever, prison systems need additional financial resources.

Most of the prevention measures outlined above, such as provision of condoms and needles and syringes, are relatively inexpensive and have been successfully implemented in resource-poor countries. Other measures, such as decreasing the use of prisons as a response to illegal drug use and limiting pre-trial detention, would free up resources by reducing the number of people in prison. Nevertheless, in order to effectively address the range of challenges that HIV poses to the effective and ethical management of prisons, and to meet recognized international standards on prison health and prison conditions, both national governments and the international community need to provide the resources necessary to develop and implement comprehensive, evidence-based interventions.

Actions that will promote an increase in resources for programmes and strategies to promote prison health, improve prison conditions, and address HIV (as well as hepatitis and TB) from *national budgets* include:

- identifying prisoners as a key vulnerable population when allocating national resources to combat HIV;
- maximizing support of peer-based HIV initiatives;
- ensuring that prisoners have access to ART under national treatment plans;
- dedicating specific funding for HIV programmes within prison budgets, and dedicating funding for prison initiatives within HIV, health, and drugs budgets;
- reviewing the impact of drug control and enforcement programmes in prisons, and examining the reallocation of funding from ineffective or counter-productive programmes into new health-based initiatives;

- ensuring that NGOs are provided with sufficient funding to play an effective role in prison HIV programmes, and that sufficient resources are provided to outside medical, drug-dependence treatment, mental health, and social services to enable them to provide post-release care for ex-prisoners.

In order to access *international funding sources*, it is essential for the ministry responsible for the prison system to be represented in national HIV coordination mechanisms, such as the National AIDS Commission and the Global Fund Country Coordination Mechanism. Whenever the government prepares proposals for HIV funding from international sources, the prison system should be included.

Checklist 8

Review of legislation and prison rules

This list contains crucial elements of legislation and prison rules concerning HIV in prisons. Check here whether legislation and prison rules in your country conform to international good practice.

- Does legislation and policy provide for access to the following HIV-related prevention, care and treatment services in prisons:
 - Information, education and communication?
 - Voluntary and confidential counselling and testing?
 - Condoms and lubricants so that prisoners can practise safer sex?
 - Sterile injecting equipment (needles, syringes and cotton swabs) for drug injecting prisoners?
 - In systems where sterile injecting equipment is not yet being provided, bleach or other disinfectants so that prisoners can attempt to clean injecting, tattooing and skin-piercing equipment?
 - Drug-dependence treatment programmes, including opioid substitution treatment?
 - Diagnosis and treatment of STI?
 - Antiretroviral treatment for prisoners with HIV?
- Does legislation and policy provide for clear standards for effective detection, prevention and reduction of prison rape and for effective prosecution of offenders?
- Does legislation and policy provide for access to post-exposure prophylaxis for staff potentially exposed to HIV during the course of their work and for prisoners who are sexually assaulted or otherwise exposed to HIV?
- Does legislation and policy provide for hepatitis vaccination for staff and prisoners?
- Does legislation and policy provide for effective TB control?
- Does legislation and policy provide for confidentiality of prisoners' medical and/or personal information, including HIV status?
- Does legislation and policy prohibit HIV discrimination in prisons, including segregation or exclusion from programmes, against prisoners living with HIV, simply on the basis of their HIV status?

- Does legislation and policy include provisions to reduce imprisonment and pre-trial detention, including by providing alternatives to imprisonment?
- Does legislation and policy allow for consideration of early release of terminally ill prisoners and provide for an accessible and quick mechanism to apply for such a release?

Reducing vulnerability among migrants, refugees, people with disabilities, and other groups

In addition to women (see Chapter 9), children (see Chapter 10), young people (see Chapter 11), men who have sex with men, people who use drugs, sex workers and prisoners, other populations are also vulnerable to HIV, and their HIV-related needs should also be addressed. They include people with disabilities, people living in poverty, migrant labourers, people in conflict and post-conflict situations, and refugees and internally displaced people.

Refugees and internally displaced persons

The 1951 Convention relating to the Status of Refugees is the key legal instrument that established a framework of basic refugee rights, including access to services. Subsequently, several important thematic and regional instruments have been adopted.¹⁵⁷

Responding to AIDS is an essential component in the protection of populations affected by emergencies and conflicts, and those in post-conflict settings. However, there are many challenges involved in protecting displaced populations – specifically refugees and internally displaced persons (IDPs) – from HIV-related discrimination. In addition, there are specific issues related to resettlement of refugees with HIV.

The *Note on HIV and AIDS and the Protection of Refugees, IDPs and Other Persons of Concern*, released by the Office of the United Nations High Commissioner for Refugees (UNHCR) in 2006 (www.unhcr.org/hiv-aids), provides an overview of how principles of refugee protection and human rights apply to persons of concern to UNHCR who are vulnerable to HIV, and serves to inform governments of recognized standards in the field of HIV, and the protection of persons of concern to UNHCR.

Parliamentarians can play an important role by advocating and supporting the full implementation of the recognized standards in the field of HIV for populations of humanitarian concern – specifically refugees and IDPs – as indicated in the *Note on HIV/AIDS*, as well as returnees and people in early

recovery or recovery situations in post-conflict countries. They can also advocate the reform of laws and policies to integrate displaced populations in the national response to AIDS.¹⁵⁸

People with disabilities

In many countries, people with disabilities constitute a significant part of the population (e.g. 12% in South Africa).¹⁵⁹ Yet this group has often been neglected in the response to AIDS. There are often erroneous perceptions that people with disabilities are asexual or do not use drugs. Many national responses have not addressed the special needs of the various categories of people with disabilities, in terms of prevention, treatment, care and support programmes. Parliamentarians can advocate the inclusion of people with disabilities in national AIDS plans and speak out for their needs.

Box 59

An example of best practice: Taking seriously the needs of people with disabilities

South Africa's *HIV & AIDS and STI National Strategic Plan (2007–2011)* explicitly acknowledges the HIV-related prevention, treatment, care and support needs, as well as the stigma- and discrimination-mitigation needs, of people with disabilities.

For a copy of the plan, see <http://www.doh.gov.za/docs/misc/stratplan-f.html>.

CHAPTER 13

A controversial issue: HIV transmission/exposure offences

Summary

Why this issue requires careful consideration

- Some jurisdictions have enacted HIV-specific criminal legislation – making it a crime to transmit or expose another person to HIV – and public calls for such legislation continue in jurisdictions where they do not yet exist.
- This raises the question of whether criminal laws and prosecutions represent sound policy responses to conduct that carries the risk of HIV transmission. On the one hand, it is obviously reprehensible for a person knowingly to infect another with HIV or any other life-endangering health condition. On the other hand, there is concern that using criminal sanctions for conduct other than clearly intentional transmission will unjustifiably infringe upon human rights and undermine other important public policy objectives. In particular, there is concern that creating HIV-specific criminal legislation will: further stigmatize persons living with HIV; provide a disincentive to HIV testing; create a false sense of security among people who are HIV-negative; and, rather than assisting women by protecting them against HIV infection, impose an additional burden and risk of violence or discrimination upon them.
- While legislating on this subject may, at first glance, seem highly popular, there is no evidence whatsoever that criminal laws specific to HIV transmission will make any significant impact on the spread of HIV and on halting the epidemic.

What you can do

- A rush to legislate on this issue should be avoided in favour of careful consideration. When considering the use of criminal sanctions, parliamentarians can use a number of guiding principles and need to take broader policy considerations into account.
- Overall, the use of criminal law may be warranted in some limited circumstances. However, criminal law should not include specific offences against transmission of HIV but should, instead, apply general criminal offences to these circumstances. The criminal law may appropriately be applied to those who intentionally transmit HIV or expose others to a significant risk of infection, while not taking precautions or not disclosing their HIV status. However, criminal liability for negligent transmission or exposure should be avoided. Even criminal liability for reckless transmission raises serious problems, including negative impact on public health efforts and evidentiary problems of proof.

Why does this issue require careful consideration by parliamentarians?

Over the last 20 years, a number of cases have been reported in which people living with HIV have been criminally charged for a variety of acts that transmit (or run the risk of transmitting) HIV. In some cases, criminal charges have been laid for conduct that is not alleged to be intentional or malicious but is merely perceived as risking transmission, sometimes with very harsh penalties imposed. Some jurisdictions have moved to enact or amend legislation specifically to address such conduct. The issue has also received public and academic commentary.

These developments have raised the question of whether criminal laws and prosecutions represent sound policy responses to conduct that carries the risk of HIV transmission. Individual cases, and accompanying media coverage, may prompt public calls for such a response. But there are few simple solutions to such a complex problem, and **a rush to legislate should be avoided in favour of careful consideration.**

On the one hand, it is obviously reprehensible for a person knowingly to infect another with HIV (or any other life-endangering health condition), by failing to take reasonable precautions or inform the person at risk so that an informed decision can be made about self-protection and exposure to risk. On the other hand, there is concern that using criminal sanctions for conduct other than clearly intentional transmission will unjustifiably infringe upon human rights and undermine other important public policy objectives.

The most recent IPU resolution specifically devoted to HIV, adopted in Manila in 2005 (see Annex 3), contained contradictory recommendations with regard to the use of criminal law. It called upon parliaments to enact seemingly very broad legislation “to punish those who knowingly take the risk of transmitting HIV/AIDS, or who wilfully do so” (paragraph 14c). At the same time, however, it called upon parliaments to “review and adjust legislation to ensure that it conforms to the *International Guidelines on HIV/AIDS and Human Rights* (paragraph 14b). According to Guideline 4 of the *International Guidelines*, however, “States should review and reform criminal laws ... to ensure that they are consistent with international human rights obligations and are not misused in the context of HIV/AIDS or targeted against vulnerable groups”.

There is an extensive body of evidence on the rights-based approach to HIV/AIDS arguing against the use of criminal law in a public health crisis like HIV/AIDS. Reasons for this include: criminalisation fuels discrimination, it does not lead to effective use of resources (including resources within the criminal justice system) and, more importantly, criminal law provisions cannot prevent the spread of HIV or the management of AIDS. In spite of this, parliaments periodically entertain discussions of this topic largely as a result of public calls for the use of criminal law. It would be more effective if parliaments continue to frame their deliberations within the broader human rights framework and craft a response that is consistent with the protection and promotion of human rights.

– IDASA (2006). *Parliaments, politics and HIV/AIDS*. Cape Town. At 22.

What parliamentarians can do¹⁶⁰

Establish clear guiding principles

When considering the use of criminal sanctions or coercive measures under public health legislation, parliamentarians may find the following principles useful.

□ **Best available evidence should be the basis of policy**

The best available scientific evidence regarding modes of HIV transmission and levels of risk must be the basis for rationally determining if, and when, conduct should attract criminal liability.

□ **Prevention of HIV should be the primary objective**

Preventing the spread of HIV should be the primary objective and this, more than any other objective, should guide parliamentarians in this area. Criminal law policy must not sacrifice the major social benefits of HIV prevention in pursuit of narrower goals with significantly less benefit to society as a whole.

□ **Policy must respect human rights**

Many years of experience in addressing the HIV epidemic have confirmed that the promotion and protection of human rights constitute an essential component in preventing transmission of HIV and reducing the impact of AIDS. Any legal or policy responses to HIV should not only be pragmatic in the overall pursuit of public health but also conform to international human rights norms.

□ **Infringements of human rights must be adequately justified**

Sometimes, public health considerations are invoked as justification for laws, policies or practices that negatively affect human rights. In some cases, such human rights restrictions are justifiable; in other cases, they are not. It is essential, therefore, that an assessment of the impact of law or policy on human rights be undertaken, and that the least intrusive measures possible be taken in order to achieve the objective of preventing disease transmission.

Take broader public policy considerations into account

There are a number of policy considerations that should be taken into account in determining criminal law policy in relation to HIV transmission or exposure. These considerations might mitigate against the use of criminal sanctions and highlight the need for caution.

Gender inequality and criminalization

In many African countries, in particular, women's rights advocates have sought to promote the criminalization of the transmission of HIV as a means of protecting women, as well as providing them with justice.

Representatives of women's rights groups have pointed out that women are ill-served by a legal and juridical framework that fails to address the effects of the 'other epidemic' – namely that of gender-based violence, particularly within long-term intimate relationships.¹⁶¹ The issues confronting women in many societies are well documented:¹⁶²

- high levels of violence against women and children
- high prevalence of multiple concurrent sexual relationships
- women's relative lack of autonomy in decision-making involving their sexual rights and health
- social and cultural norms that place and keep women in a subordinate position within their society
- inheritance and property laws that leave women and children vulnerable to impoverishment and its attendant ills.

As a result, women are more vulnerable to infection, more likely to face multiple layers of discrimination and violence, and less likely to receive the services that should be in place to defend them from violence, disease and death.

However, criminalization of HIV transmission or endangerment does not represent an effective way to deal with the entrenched and complex problem of violence against women. Indeed, it is women themselves who potentially stand to be the most harmed by laws criminalizing HIV transmission or endangerment.¹⁶³

Women are more likely to know their HIV status due to their health-seeking behaviour, and would therefore be at greater risk of being prosecuted under new, HIV-specific criminal laws.

- The trend towards provider-initiated HIV testing (see Chapter 5) will result in even more women knowing their HIV status and thus being exposed to criminal liability under HIV-specific criminal laws. To avoid the risk of being prosecuted, women who test HIV-positive would have to disclose their HIV status to their intimate partners, thus placing themselves at risk of violence, loss of child custody, disinheritance, and other abuses. The combination of more routine forms of testing (particularly during pregnancy) and criminalization thus places women in a difficult position.
- Men are more likely to access traditional court systems (most of which have some level of recognition within African legal systems), and are more

likely to receive a favourable outcome in highly patriarchal customary law systems. This may also result in women being more likely to be victimized by criminalization trends.

- Experience suggests that women are more likely to be blamed by their communities for ‘bringing HIV into the home’ than men, and that this can result in eviction, ostracism, and loss of property and inheritance. This is especially true in so far as apportionment of blame is still an important part of both customary and formal legal systems in East and Southern Africa in relation to divorce and inheritance. As noted above, the pressure to disclose one’s HIV status, exerted by HIV-specific criminal law, increases these risks for women.

Therefore, parliamentarians should take into account the effect of invoking the criminal law against women living with HIV. For women who are unable to disclose their HIV status or to take precautions to reduce the risk of transmission, invoking the criminal law may not ultimately serve to protect them, and may, instead, impose an additional burden and risk of violence or discrimination.

Chapter 9 in this Handbook suggests many actions that parliamentarians can take to address violence against women.

Reinforcing HIV-related stigma

Introducing HIV-specific criminal laws, or inflammatory media coverage or statements by public figures regarding individual prosecutions, may contribute to the stigma surrounding AIDS and people living with HIV.

Disincentive to HIV testing

If someone who is aware of their HIV-positive status is exposed to possible criminal prosecution, any effect the criminal law has in deterring risky activity could ultimately be outweighed by the harm it does to public health by deterring people from seeking HIV testing.

Creating a false sense of security

Criminalizing could create a false sense of security among people who are (or think they are) HIV-negative, because some may expect that the existence of criminal prohibition for ‘other’ (i.e. HIV-positive) people reduces the risk involved in having unprotected sex. This could undermine the public health message that everyone should take measures to reduce or avoid activities that could increase their risk of HIV transmission.

Difficulties with proof

There may be a number of difficulties in proving certain required elements of an offence beyond a reasonable doubt in order to obtain a conviction, such as: whether the accused knew of their HIV-positive status at the time of the alleged offence; that it was the accused who actually infected the complainant; or that the HIV-positive person did not disclose their status to the complainant.

Hindering access to counselling and support

Criminalizing risky conduct by people living with HIV could undermine their confidence in counsellors if the information discussed with a counsellor is not protected by confidentiality rules from search and seizure by police and prosecutors.

Risk of selective prosecution

There is a risk that criminal sanctions will be directed disproportionately at those who are socially, culturally or economically marginalized.

Consider a number of key questions

Overall, the use of the criminal law may be warranted in some limited circumstances, but there are many important policy considerations that need to be taken into account, which may, upon reflection, lead parliamentarians to conclude that legislating in this area is not helpful to the AIDS response and should be avoided. Where criminalization is deemed an option, at least three major questions will have to be addressed in determining its parameters.

Should HIV-specific legislation be enacted?

Enacting HIV-specific criminal statutes could lead to a clearer definition of what is prohibited than if it were left to the courts to decide how traditional offences apply to HIV transmission/exposure. However, **there are many arguments against HIV-specific statutes.** They may be unnecessary, given existing criminal offences. Most importantly, however, they would single out people living with HIV as potential criminals, and single out HIV among other STIs, contributing to stigma and discrimination and undermining other HIV prevention and care efforts.

Box 60**Examples of law and policy on criminal law and HIV**

- In South Africa, the Law Reform Commission has advised against creating a specific offence aimed at “AIDS-related behaviour”.
- In Sweden, there is no HIV-specific criminal offence; the public health statute grants authority to public health authorities to intervene in the event that a person is spreading, or is suspected of spreading, a communicable disease.

Which acts should be subject to criminal prohibition?**Transmission versus exposure**

Should criminal liability exist only where conduct actually results in HIV transmission, or should it extend to some conduct that risks transmitting HIV even if, in a given case, there is no actual transmission?

Some argue that the application of the criminal law should be limited to cases of actual HIV transmission, and that it is inappropriate and undesirable to extend the law to also criminalize exposure to HIV. There is concern that the law would extend far too broadly if it were to criminalize exposure to HIV infection. It has also been suggested that the per-act risk of transmitting HIV associated with various sexual acts is low enough that the criminal law should not be enacted merely for instances of exposure.

Others argue that, if preventing HIV transmission is the primary objective, it makes most sense for the law to target conduct that creates a risk of transmission, rather than imposing criminal penalties only in those cases where the risk actually materializes and infection actually occurs.¹⁶⁴

A compromise position is to recognize that it may be appropriate for the criminal law to apply to some circumstances in which a person exposes another to the risk of infection, but only if the person has the intent to transmit HIV.

Degree of risk

Only conduct that carries a significant risk of HIV transmission may legitimately be criminalized. Extending the criminal law to actions that pose no significant risk of transmission would:

- trivialize the use of criminal sanctions;
- impose harsh penalties disproportionate to any possible offence;
- undermine HIV prevention efforts by perpetuating the misperception that the conduct in question must carry a significant risk of transmission because it has been targeted for criminal prosecution.

The nature of the conduct: coercive versus consensual

Conduct that involves the risk of HIV transmission may be either coercive (e.g. rape, stabbing with a needle) or may be an activity to which the participants are ostensibly consenting (e.g. consensual sex, sharing injecting equipment).

Physically assaultive conduct is criminal in itself, regardless of whether it carries any risk of HIV infection. It is the assaultive conduct, not the HIV status of the offender, that is relevant in determining whether or not a crime has been committed.

In some cases, the fact that the offender is HIV-positive may appropriately be treated as an aggravating factor because there was an additional risk of harm. But not all assaultive conduct carries a significant risk of HIV transmission. More serious criminal charges (or harsher penalties), on the basis of an offender's HIV-positive status, can only be justified if there is evidence that the assaultive conduct carried a significant risk of HIV transmission.

Applying the criminal law to ostensibly consensual activity that carries the risk of HIV transmission (e.g. sex, sharing injecting equipment) is far more complicated. Certainly, the individual who is aware of a partner's HIV infection and, with that knowledge, engages in sexual or needle-sharing activity that risks transmission, is consenting to that risk of harm, even if there is a very significant risk. HIV-positive persons whose partners are competent adults and consent to taking this known risk should not be criminalized.

But should it be a criminal offence for a person who knows they are HIV-positive to obtain a partner's 'consent' for conduct that involves the risk of HIV transmission by deceit – that is, actively misrepresenting the fact that she/he is HIV-negative? Should criminal liability extend further, to cases of simple non-disclosure of HIV-positive status to the other person who is participating in an activity that puts him/her at risk of infection? It has been suggested that criminal sanctions may be applied to cases of deceit, but that mere non-disclosure of HIV-positive status should not amount to a criminal offence.

Sexual activity, with any partner, always carries some risk of harm, whether it be unwanted pregnancy or disease. A person engaging in sex does not need to know the HIV status of the sexual partner in order to make meaningful choices. He or she may choose not to engage in certain sexual acts, may choose to take preventive measures to lower the risk to a level they find acceptable (e.g. condom use), or may choose to engage in unprotected sex, aware that a risk of HIV transmission may exist. Furthermore, unlike the

case of deliberate deceit, in the case of simple non-disclosure, the partner of the HIV-positive person has not been misled into basing choices on wilful misinformation. While promoting respect for autonomy might justify criminal penalties for deliberate deceit, it is a weaker argument for criminalizing mere silence.

A criminal law requiring disclosure of HIV infection would fall most heavily upon those whose circumstances already make it difficult to disclose. At the very least, if the law were to extend this far, any duty to disclose HIV infection should be qualified: the law should recognize that criminal liability could be avoided by taking precautions to reduce the risk of transmission (e.g. by practising safer sex). Indeed, allowing the HIV-positive person to avoid criminal liability by taking precautions is good public policy. **To criminalize the HIV-positive person who, although refraining from disclosure, actually practises safer sex, would be directly counter-productive to the very goal of preventing further transmission.**

What degree of mental culpability should be required for criminal liability?

The criminal law must define not only the conduct that is prohibited, but also when that conduct is culpable and when it is innocent. The criminal law recognizes different degrees of mental culpability, and not all of them will justify criminal prosecution and punishment in all circumstances. In general, the law recognizes three levels of mental culpability.

- **Intent:** From a legal perspective, a person *intentionally* commits a crime either when it is his or her *purpose* to commit it, or if he/she *knows* with some certainty that his or her conduct will bring about the prohibited result. The exact characterization of the degree of certainty required may vary across jurisdictions, even within jurisdictions sharing the same basic legal tradition.
- **Recklessness:** A person is criminally *reckless* when he or she foresees that his or her conduct may cause the prohibited result but, nevertheless, takes a deliberate and unjustified risk of bringing it about. In other words, in order to be reckless, a person must be aware that their conduct carries a risk of harm, and *unjustifiably* run that risk. While reckless conduct is sometimes prohibited and punished with the weight of criminal law, this is not always the case. This will depend on how the offence is defined.
- **Negligence:** As a general rule, a person must either intentionally or recklessly commit an offence in order to be found guilty. Ordinarily, conduct that is merely negligent is not subject to criminal sanction (although it may attract civil liability). In a few circumstances, negligent conduct may attract criminal liability. In such cases, the person is deemed blameworthy

and deserving of punishment because they failed to be aware of the possible harm from their conduct. However, even in such cases, generally it is *gross negligence* (more than mere, ordinary negligence) that must be proved in order for the individual in question to be judged guilty of a crime. In other words, the conduct must markedly deviate from the ordinary care that would have been exercised by a ‘reasonable person’.

It is generally agreed that criminalization could be justified in cases of conduct that *intentionally* transmits HIV. Whether the criminal law should extend to reckless or negligent conduct in the context of HIV transmission/exposure is more questionable. It has been argued that the criminal law may appropriately be applied to those who recklessly transmit HIV or expose others to a significant risk of infection, as, in these cases, the person is aware that their conduct carries a significant risk of harming another. However, criminal liability for negligent transmission or exposure should be avoided, given the absence of this awareness, and the persistence of misinformation about modes of transmission and levels of risk.

Regardless of which level of mental culpability is deemed sufficient to impose liability, basic principles of fairness in the criminal law require that the accused person who engages in activity that transmits HIV or risks transmission must be aware of their HIV status before any criminal liability could arise. Furthermore, in order to be held criminally liable, the HIV-positive person should understand that the conduct of which they are accused posed a significant risk of HIV transmission.

Consider public health law as an alternative to criminalization

Public health laws should be considered as a possible alternative to the use of criminal law. While public health laws vary from jurisdiction to jurisdiction, with respect to transmissible diseases, their three primary functions are to:¹⁶⁵

- classify transmissible diseases, specifying which legal provisions apply to which diseases;
- impose legal duties on certain people (e.g. physicians) to identify, report and treat diseases;
- grant powers to public health officials to be exercised in the prevention and treatment of diseases.

At the most coercive extreme, public health laws take on a quasi-criminal character. Health officials may have the power to compel those suspected of being infected with a transmissible disease to undergo examination and medical treatment. They may also order an infected person to conduct themselves in such a manner as to avoid, or reduce the likelihood of, infect-

ing others. An example would be an order prohibiting a HIV-positive person from having unprotected sex and/or ordering that person to disclose his or her HIV infection to sexual partners. Depending on the legislation in question, breaches of such public health orders could result in penalties such as fines or imprisonment; or such orders could be backed up by court orders, with similar penalties for breaching a court-issued order. Health officials also generally have the power to detain a person if this is demonstrably justified as necessary to prevent the transmission of disease (generally and preferably in a health-care setting, although, again, legislation and practice may vary across jurisdictions). The law may authorize the use of the State's police powers to enforce detention orders by public health officials.

If, on balance, the use of public health powers can achieve the objectives said to be served by criminalization, while doing less damage to public health initiatives and other important interests (such as rights to non-discrimination, due process, and privacy), then resorting to the criminal law may be unnecessary and unjustified.

Box 61

Key resources on criminal law and HIV

➔ UNAIDS (2002). *Criminal law, public health and HIV transmission: A policy options paper*. Geneva: UNAIDS 2002 (www.unaids.org)

Checklist 9

Criminal law and HIV transmission/exposure: Key issues

This list contains key considerations that should inform the development of sound public policy in this area. Check here whether your country conforms to international good practice.

- Use coercive measures as a last resort:** Consider the use of public health laws as an alternative to criminalization. Criminal prosecutions, as the most coercive and stigmatizing of measures, should be reserved for those cases where public health interventions have not succeeded in achieving the objective of preventing further HIV transmission. Protocols should be developed to ensure coordination between public health officials, law enforcement and prosecutors.
- No HIV-specific legislation:** Criminal and/or public health legislation should not include specific offences against the deliberate and intentional transmission of HIV but should, instead, apply general criminal offences to these exceptional cases.
- Consent a complete bar to criminal liability:** Criminal charges should not apply to an HIV-positive person for conduct that poses a risk of transmission if the partner at risk is aware of the other individual's HIV-positive status, regardless of the degree of risk involved.

- **No criminal sanctions for mere non-disclosure of HIV-positive status:** Whether by statute or by judicial determination, the law should expressly recognize that there is no criminal liability for HIV transmission or exposure when the conduct, in and of itself, carries no significant risk of transmitting HIV; or the HIV-positive person has taken precautions to reduce the risk of transmission, such that it is no longer significant, regardless of whether they have misrepresented or simply not disclosed their HIV status; or the HIV-positive person would risk serious harm to her/himself by disclosing her/his HIV status.
- **No criminal liability for negligent transmission or exposure:** The criminal law may appropriately be applied to those who intentionally or recklessly transmit HIV or expose others to a significant risk of infection, as, in these cases, the person is aware that their conduct risks harming another. However, criminal liability for negligent transmission or exposure should be avoided, given the absence of this awareness and the persistence of misinformation about modes of transmission and levels of risk.

PART III

*Useful background information
for parliamentarians*

Annex 1

Basic facts about AIDS

HIV is the **human immunodeficiency virus**. HIV damages the body's immune system, weakening it until it can no longer fight off other diseases. People infected with HIV usually live for years without any signs of disease and look and feel healthy. A blood test is the most accurate way for a person to know if he or she is infected with HIV; saliva and urine tests are now also available.

AIDS, or **acquired immune deficiency syndrome**, is the late stage of HIV infection. People who have AIDS grow weaker because their bodies lose the ability to fight off illnesses. The most common sicknesses that kill people with AIDS are TB, pneumonia, diarrhoeal diseases and certain cancers. In adults, AIDS on average develops 7–10 years after infection with HIV. In young children, the disease usually develops much faster.

Medicines can help people with HIV or AIDS live healthier and longer lives and can prevent transmission of HIV from mothers to their infants. An increasing number of people living with HIV or AIDS have access to life-prolonging antiretroviral medicines.

So far, there is no **vaccine** or **cure**. But treatment with antiretroviral medicines is effective in keeping people healthy – generally for many years and sometimes indefinitely.

HIV spreads through:

- unprotected sexual intercourse (the cause of the vast majority of infections);
- transfusion of HIV-contaminated blood;
- contaminated needles and syringes (most often those used for injecting drugs, but some of the new infections every year result from the failure to maintain sterilization in health services);
- from an infected woman to her child during pregnancy, childbirth or breastfeeding.

The virus only spreads when certain bodily fluids – blood, semen, vaginal fluid and breast milk – of an infected person pass into the body of another person. (Saliva, tears and urine do not spread HIV.) The virus multiplies in the body so rapidly that, within hours, newly infected persons themselves become infectious.

HIV is not spread through everyday contact such as shaking hands, kissing, touching, sharing cups or plates, sharing toilets, staying in the same office or house as a person who has HIV, or through swimming pools, public baths or bites from mosquitoes or other insects.

➔ *For additional information about HIV basics, see a great number of publications with basic information about HIV available via <http://www.thebody.com/index/whatis/basics.html>, or click on 'HIV basics' at www.aidsmap.com.*

Annex 2

Which human rights are particularly important in the context of HIV?

There is no international treaty or covenant that specifically addresses AIDS. However, a number of provisions from international human rights treaties and declarations have significant implications for the effectiveness of the response to AIDS. **Parliamentarians should check whether their government has ratified the core treaties and the existing regional treaties and, if not, take action to ensure that it does.**¹⁶⁶ The provisions that have implications for the response to AIDS include the following.¹⁶⁷

The right to the highest attainable standard of health. The International Covenant on Economic, Social and Cultural Rights (ICESCR) recognizes the right of everybody to the enjoyment of the highest attainable standard of physical and mental health. As part of this obligation, States must take steps to prevent, treat and control epidemic diseases. The obligations of the State include the provision of appropriate HIV-related information, education and support; and access to the means of prevention (such as condoms and clean injecting equipment), to voluntary counselling and testing, to safe blood supplies, to adequate HIV treatment and medications (such as antiretrovirals), to medicines for opportunistic infections, and to medicines for pain and palliative care. States may have to take special measures to ensure that all groups in society (particularly members of marginalized populations) have equal access to HIV-related prevention, treatment, care and support.

The right to life. The International Covenant on Civil and Political Rights (ICCPR) recognizes that “every human being has the inherent right to life”. Interpreting the right to life, the Human Rights Committee has recommended that Namibia “pursue efforts to protect population from HIV/AIDS” and “adopt comprehensive measures encouraging greater numbers of persons suffering from HIV and AIDS to obtain adequate antiretroviral treatment and facilitate such treatment” (2004). It has also called for “equal access to treatment” in Kenya (2005) and for Uganda to “allow greater number of persons suffering from HIV/AIDS to obtain adequate treatment” (2004).¹⁶⁸

Non-discrimination and equality before the law. International human rights law guarantees the right to equal protection before the law and freedom from discrimination on many grounds.¹⁶⁹ The Commission on Human Rights has confirmed that “other status” in non-discrimination

provisions in international human rights treaties is to be interpreted to include health status, including HIV status.¹⁷⁰

Human rights of women. Protection of the rights of women and girls – including sexual and reproductive rights – is critical to preventing HIV transmission and to lessening the impact of the epidemic on women. The Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW) obliges States parties to address all aspects of gender-based discrimination in law, policy and practice.

Human rights of children. Under the Convention on the Rights of the Child (CRC), children are confirmed to have many of the rights of adults, in addition to particular rights for children, which are relevant in relation to HIV. Children have the right to freedom from trafficking, prostitution, sexual exploitation and sexual abuse; the right to seek, receive and impart HIV information; and the right to special protection and assistance, if deprived of their family environment. They also have the right to education, the right to health and the right to inherit property. The right to special protection and assistance, if deprived of his or her family environment, protects children if they are orphaned by AIDS, and the right of children to be actors in their own development and to express their opinions empowers children to be involved in the design and implementation of HIV-related programmes for children.

Right to marry and found a family. The ICCPR recognizes the right to marry and found a family.¹⁷¹ Mandatory pre-marital testing as a precondition to marriage, or forced abortions or sterilization of women living with HIV, violates these (and other) rights.

Right to privacy. This right, set out in the ICCPR, encompasses obligations to respect physical privacy (e.g. the obligation to seek informed consent to HIV testing) and the need to respect confidentiality of personal information (e.g. information relating to a person's HIV status).

Right to education. This right, provided for by Article 26 of the *Universal Declaration of Human Rights* (UDHR) and Article 13 of the *ICESCR*, guarantees that those living with HIV are not discriminatorily denied access to education on the basis of their HIV status. The right to education also encompasses the obligation of States to promote understanding, respect, tolerance and non-discrimination in relation to people living with HIV, and provides that individuals have the right to receive HIV-related education.¹⁷²

Freedom of expression and information. Article 19 of the ICCPR provides for the right to seek, receive and impart information related to HIV prevention, treatment, care and support. States are obliged to ensure that informa-

tion on methods to prevent HIV transmission is developed and disseminated without obstacles to access.

Freedom of assembly and association. The right to peaceful assembly and association, provided by Article 20 of the UDHR and by Article 22 in the ICCPR, has frequently been denied to civil society organizations working on human rights and HIV. Organizations should enjoy the rights and freedoms recognized in human rights instruments and the protection of national law. HIV-positive people should be protected against discrimination based on HIV status in admission to trade unions and other organizations.

Right to work. This right, enshrined in Article 23 of the UDHR and Articles 6 and 7 of the ICESCR, entails the right of every person to access employment without any precondition except the necessary occupational conditions. This right is violated when an applicant or employee is required to undergo mandatory testing for HIV and is dismissed or refused employment on the grounds of a positive result. The right to work further guarantees the right to safe and healthy working conditions. Where a possibility of HIV transmission exists, States should take measures to minimize these risks.

Right to enjoy the benefits of scientific progress and its applications. This right, set forth in Article 27 of the UDHR and Article 15 of the ICESCR, is important in relation to HIV in view of scientific and pharmaceutical advances made in diagnosis and treatment, as well as in the development of a vaccine and new prevention tools such as microbicides. This right also obliges the State to ensure that treatment and participation in clinical trials are made equally available to women and children, as well as to marginalized and vulnerable populations.

Right to freedom of movement. This right, found in Article 12 of the ICCPR and Article 13 of the UDHR, encompasses the right of everyone to freely choose his/her place of residence within a country, as well as the rights of nationals to enter and leave their own country. As there is no public health rationale for restricting liberty of movement or choice of residence for people living with HIV, or for restricting travel, such restrictions would be discriminatory.

Right to an adequate standard of living and social security services. The enjoyment of this right, found in Article 25 of the UDHR and in Articles 9 and 11 of the ICESCR, is essential to reducing the impact of HIV on people living with HIV, families impoverished by AIDS, and children orphaned or otherwise made vulnerable by HIV. States should ensure that people living with HIV are not discriminatorily denied an adequate standard of living or

social security services, that families, caregivers and children affected by HIV are protected from food insecurity and impoverishment caused by AIDS, that the property of AIDS widows is not grabbed, and that the inheritance of children is not taken.

Right to participation in political and cultural life. This right, found in Article 25 of the ICCPR and Article 15 of the ICESCR, is essential for ensuring the participation of those most affected by HIV in all aspects of HIV-related policies and programmes.

Right to seek and enjoy asylum. Everyone has the right to seek and enjoy asylum from persecution in other countries. Under the 1951 Convention relating to the Status of Refugees and under customary international law, States cannot return refugees to a country where they face persecution or torture. Thus, States may not return refugees to persecution on the basis of their HIV status. Furthermore, they cannot undertake special measures, such as mandatory HIV testing, to exclude HIV-positive people from asylum.

Right to liberty and security of person. This right, found in Article 9 of the ICCPR, means that the right to liberty and security should not be arbitrarily interfered with, based merely on a person's HIV-status (e.g. by placing an HIV-positive individual in quarantine or isolation). Also compulsory HIV testing can constitute a deprivation of liberty and a violation of the right to security of person. Respect for the right to physical integrity requires that testing be voluntary and undertaken with the informed consent of the person.

Freedom from cruel, inhuman or degrading treatment or punishment. This right, found in Article 5 of the UDHR and Article 7 of the ICCPR, provides for the State to ensure that prisoners have access to HIV-related information, education and means of protection (such as condoms and clean injection equipment) as well as voluntary counselling and testing and treatment. This right also comprises the State's duty to combat prison rape and other kinds of sexual victimization in prison.

Annex 3

The IPU takes action

The Inter-Parliamentary Union (IPU) has devoted sustained attention to supporting the response to the AIDS epidemic.

A number of IPU resolutions on AIDS have highlighted the roles of parliaments and their members in the response to AIDS.

1992: A resolution adopted by the 87th Inter-Parliamentary Conference in Yaoundé called on parliamentarians to acknowledge the scope of the pandemic and to press their respective governments and community and religious leaders to pursue a comprehensive strategy for controlling the spread of HIV. It urged governments to ensure protection of the human rights and civil liberties of people infected, or believed to be infected, by HIV.

1998: A resolution adopted by the 99th IPU Conference in Windhoek requested that UNAIDS, in cooperation with the IPU, develop the first edition of the Handbook and disseminate it as a reference tool for establishing appropriate legal standards.

2001: A resolution adopted by the 106th IPU Conference in Ouagadougou called on all parliamentarians to step up their efforts to establish effective national and international HIV policies and programmes, specifically tailored to the needs of the various target groups. It also called on all governments to give human rights precedence over trade rights, to incorporate them into trade rules, and to take account of human rights standards in the WTO TRIPS Agreement. It urged them to ensure the protection of human rights by drawing on the *International Guidelines on HIV/AIDS and Human Rights*, and on the *ILO Code of Practice on HIV/AIDS and the World of Work*. It called for special attention to be given to the prevention of HIV.

2005: The most recent and comprehensive resolution on HIV was adopted in Manila by the 112th Assembly. It is reproduced in full at the end of this annex.

In addition to these HIV-specific resolutions, many other resolutions, such as the resolution on migration and development adopted by the 113th Assembly, have addressed issues related to HIV. Other important activities include IPU participation in UN processes on HIV, panel discussions on HIV held during IPU Assemblies, and the establishment of the IPU Advisory Group on HIV/AIDS.

2006–2007: The first meeting of the IPU Advisory Group was held in Geneva on 18 and 19 September 2006. The Group met to discuss the HIV epidemic and the need for greater involvement of parliaments in scaling up the worldwide response to AIDS. The members agreed that the Group's major focus should be advocacy – primarily within parliaments – to improve understanding of HIV among parliamentarians, and subsequently to influence governments and the general public. The Group further agreed that parliamentary oversight in the response to AIDS should include field visits, scrutiny of compliance with the commitments contained in the 2006 *Political Declaration on HIV/AIDS*, and monitoring of observance of the UNGASS reporting process.

➔ *For additional information about the IPU's involvement in HIV activities, see: www.ipu.org*

The Role of Parliaments in Advocating and Enforcing Observance of Human Rights in the Strategies for the Prevention, Management and Treatment of the HIV/AIDS Pandemic

Resolution adopted unanimously by the 112th Assembly (Manila, 8 April 2005)

The 112th Assembly of the Inter-Parliamentary Union,

Recalling the relevant resolutions of the IPU, especially the resolution entitled Action to combat HIV/AIDS in view of its devastating human, economic and social impact, adopted in Windhoek in 1998, and convinced that HIV/AIDS is an all-embracing threat against development, rather than an isolated health problem,

Further recalling the International Guidelines on HIV/AIDS and Human Rights, issued by the Joint United Nations Programme on HIV/AIDS (UNAIDS) and the Office of the United Nations High Commissioner for Human Rights (OHCHR) in 1998, and the *Declaration of Commitment on HIV/AIDS "Global Crisis – Global Action"* adopted by the United Nations General Assembly Special Session on HIV/AIDS in 2001,

Taking note of the UNAIDS 2004 *Report on the global AIDS epidemic*,

Affirming the recommendations contained in the document *Guidance on ethics and equitable access to HIV treatment and care*, issued by UNAIDS and the World Health Organization (WHO),

Referring to the Handbook for Legislators on HIV/AIDS, Law and Human Rights, published jointly by the IPU and UNAIDS in 1999,

Reaffirming the Millennium Development Goal (MDG) contained in the United Nations Millennium Declaration, which aims to halt and begin to reverse, by 2015, the spread of HIV/AIDS,

Aware that the achievement of all MDGs, including those concerning education and food security, will not be feasible unless progress is made in addressing the challenge of HIV/AIDS and other communicable diseases,

Deeply concerned that each year the number of people infected with HIV continues to grow, and *also deeply concerned* by the exponential growth in the number of women, young people and children affected by HIV/AIDS,

Recognising that discrimination against women, both de jure and de facto, renders them particularly vulnerable to HIV/AIDS,

Alarmed by the unprecedented number of children around the world who are being orphaned by HIV/AIDS, who are thus rendered far more vulnerable and face a much greater risk of hunger, of having limited access to education, health and social services, and of violence, abuse, exploitation and recruitment as child soldiers, and *aware* that these factors increase their likelihood of becoming infected with HIV themselves,

Further concerned that the reluctance of some governments to acknowledge the existence and gravity of the HIV/AIDS pandemic, and to recognise the stigma and discrimination faced by people living with HIV/AIDS, particularly women, hampers the effectiveness of responses to this pandemic,

Aware that stigma and discrimination continue to prevent people from having access to HIV testing and counselling services, which are of paramount importance in the prevention and treatment of the pandemic,

Recognising that the global HIV/AIDS pandemic constitutes a formidable challenge to human life and dignity and to the full enjoyment of human rights, and that the full realisation of human rights and fundamental freedoms for the people affected is an essential element in the global response to the pandemic,

Affirming that respect for, and the protection and fulfilment of, the human rights of women and girls are necessary and fundamental components of the approach to addressing HIV/AIDS,

Concerned about the negative economic and social impact of the denial of the human rights of people living with HIV/AIDS to work, education and other social services, and *further concerned* that women and children often suffer the greatest economic and social impact as a result of the pandemic,

Underscoring that the struggle against HIV/AIDS cannot be separated from the struggle against poverty, which affects primarily women and children, thus undermining the workforce and hindering economic and social development,

Concerned that ignorance and intolerance are still a reason for the marginalisation of persons affected or presumed to be affected by HIV/AIDS, which causes discriminatory acts in the fields of medical assistance, job opportunities, education, housing and, in general, in every aspect related to their social well-being,

Considering that although the use of antiretroviral medications combined with proper therapies can delay the advance of HIV/AIDS, millions of infected people in developing nations, particularly in Africa, cannot afford these treatments,

Considering that under the Agreement on Trade-Related Aspects of Intellectual Property Rights (TRIPS Agreement) of the World Trade Organization (WTO), WTO members may allow the production of patented medicines in the event of health emergencies, and *realising* that the World Health Assembly passed a resolution encouraging WHO Member States to utilise fully the flexibilities in the TRIPS Agreement to promote access to antiretrovirals and other essential pharmaceutical products,

Aware that the realisation of the rights of people living with HIV/AIDS requires non-discriminatory access for them to services, including health care, treatment and social and legal services, within a supportive social environment,

Convinced that recognising the degree of the infection levels of the HIV/AIDS pandemic within each country will help the respective governments tailor their prevention and treatment programmes to meet their particular needs,

Further convinced that capacity-building in the field of public health is critical to the effective prevention and treatment of HIV/AIDS,

Also convinced that countries particularly affected by the HIV/AIDS pandemic should receive special support from the international community for their efforts to comply with their commitments,

Considering that ensuring access to affordable medication, including access to anti-retroviral therapy for those suffering from HIV/AIDS, is fundamental to achieving progressively the full realisation of the universal right to the enjoyment of the highest attainable standard of health,

Considering that conflict situations, particularly in Africa, have led to an increased incidence of HIV/AIDS, and recalling United Nations Security Council resolution 1308 (2000), which states that the HIV/AIDS pandemic, if unchecked, may pose a risk to stability and security, and the report of the United Nations High-Level Panel on Threats, Challenges and Change, which places infectious diseases among the economic and social threats to international security,

Aware of the fact that any response to the epidemic will be effective only if it addresses the causes of its spread, including human trafficking, in particular trafficking in women and girls, drug abuse and illicit drug trafficking and gender-based violence, and considering in this context that the pivotal roles of the family, religion and long-established fundamental ethical principles and values need to be underlined,

Emphasising that the HIV/AIDS pandemic is at the same time a medical, social and economic emergency,

1. *Calls upon* parliaments and governments to ensure that their laws, policies and practices respect human rights in the context of HIV/AIDS, in particular the rights to education, work, privacy, protection and access to care, treatment and social services; and *also calls upon* them to protect people living with HIV/AIDS from all forms of discrimination in both the public and the private sectors, promote gender equality, ensure privacy and confidentiality in research involving human subjects, and provide for speedy and effective judicial, administrative and civil remedies in the event that the rights of people living with HIV/AIDS are violated;

2. *Reminds* States of the commitments they have made to promote and encourage respect for human rights instruments such as the Universal Declaration of Human Rights, the International Covenant on Economic, Social and Cultural Rights, the International Covenant on Civil and Political Rights, the Convention on the Elimination of All Forms of Discrimination against Women and its Optional Protocols, the Convention on the Rights of the Child, the Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment, the International Convention on the Elimination of All Forms of Racial Discrimination, and the Declaration on Fundamental Rights and Principles at Work of the International Labour Organization; and *requests* States that have not yet done so to take the necessary steps to ratify and implement these international instruments;
3. *Invites* States that have not already done so to include in their national reports on the MDGs the objective of stopping by 2015 the spread of HIV/AIDS and of beginning to reverse the development of this pandemic; *further invites* parliaments to sponsor the official launch of these reports from their premises; and *encourages* the periodic establishment of national and regional reports taking stock of the degree of achievement of the MDGs, in particular in the field of the fight against HIV/AIDS;
4. *Urges* governments in the developed countries both to continue and to increase the financial and technical assistance that they provide to developing countries and especially the least developed countries, and to share their expertise in addressing HIV/AIDS with those countries that seek to create or strengthen their own human rights institutions in the context of HIV/AIDS;
5. *Further urges* governments to allocate sufficient resources to their health systems, including resources for prevention and care;
6. *Strongly urges* governments to implement the measures recommended in the UNAIDS/WHO document *Guidance on ethics and equitable access to HIV treatment and care* to promote equity in the distribution of HIV care in resource-limited settings;
7. *Further urges* parliaments and governments to adopt and finance the measures necessary to ensure, on a sustained basis and for all affected persons (irrespective of social status, legal situation, gender, age or sexual orientation), the availability and accessibility of good quality services and information for HIV/AIDS prevention, management, treatment, care and support, including the provision of HIV/AIDS prevention supplies such as male and female condoms, safe injection needles, microbicides and basic preventive care materials, as well as affordable antiretroviral drugs and other safe and effective medicines in poor countries, psychological support, diagnostics and related technologies, for all persons, with particular attention to vulnerable individuals and populations such as women and children;
8. *Also urges* parliaments and governments to implement measures to increase the capacity of women and adolescent girls to protect themselves from the risk of HIV infection, principally through the provision of health care and health services, including those related to sexual and reproductive health;

9. *Invites* parliaments and governments to adopt the measures necessary to continue, intensify, combine, make mutually beneficial and harmonise national and multinational research and development efforts aimed at developing new treatments for the fight against HIV/AIDS, new means of prevention and new diagnostic tools and tests, including vaccines and female-controlled prevention methods such as microbicides;
10. *Calls upon* parliaments and governments to recognise the health, socio-economic and other effects of HIV/AIDS on individuals, families, societies and nations, and to take the appropriate legislative and executive social measures to halt its spread;
11. *Calls upon* governments to make services related to treatment, care and support for people living with HIV/AIDS comprehensive, by including the prevention and treatment of other infectious diseases often associated with HIV/AIDS, such as pneumonia, tuberculosis and opportunistic infections;
12. *Urges* all parliaments and governments to adopt and implement policies that respect the human rights of persons living with HIV/AIDS, and through all available media, to advocate for and raise awareness of their rights;
13. *Calls upon* parliaments and governments to develop and implement national legislation and policies that address the needs and human rights of the growing number of children orphaned and made vulnerable by the HIV/AIDS pandemic;
14. *Calls upon* parliaments:
 - (a) to draw up laws or amend existing legislation to define national standards of protection for those suffering from HIV/AIDS, and especially for people in vulnerable groups, such as women and children, with particular attention paid to the situation of anyone suffering from the loss of close family members as a result of HIV/AIDS;
 - (b) to review and adjust legislation to ensure that it conforms to the *International Guidelines on HIV/AIDS and Human Rights*;
 - (c) to enact legislation to punish those who knowingly take the risk of transmitting HIV/AIDS, or who wilfully do so;
15. *Further calls upon* parliamentarians in the IPU's Member Parliaments to promote appropriate legislative measures to tackle discrimination against persons affected by HIV/AIDS and to contribute to the creation of a social environment of tolerance and human solidarity, indispensable for the prevention of this terrible disease and for assisting those affected by it;
16. *Also calls upon* parliaments, governments and the international community to ensure free access to HIV testing for all;
17. *Calls upon* parliaments to promote an effective and efficient use of resources for HIV/AIDS response, including by means of country-level coordination that takes into consideration the UNAIDS "Three Ones" guiding principles for national authorities and their partners;
18. *Urges* parliaments to create parliamentary committees and/or other structures formally linked to parliaments with the specific task of tackling the issue of halting and reversing the spread of HIV/AIDS, to share experiences, information

and best practices and to involve all sectors of society through partnership programmes in high-level decision-making processes;

19. *Calls upon* organisations, agencies, bodies, funds and programmes within the United Nations system to incorporate public health into their development activities and programmes, and to support actively the capacity-building of the public health systems of Member States in respect of the prevention and treatment of HIV/AIDS;
20. *Urges* parliaments and governments to take into consideration the linkage between sexual and reproductive health and rights on the one hand, and the fight against HIV/AIDS on the other;
21. *Further urges* parliaments to develop comprehensive policies to provide for an improved food supply in countries affected by the HIV/AIDS pandemic;
22. *Calls upon* parliaments and governments to ensure the development and accelerated implementation of national strategies for women's empowerment, inter alia by ensuring they have access to property rights, by promoting and protecting women's full enjoyment of all human rights and by reducing their vulnerability to HIV/AIDS through the elimination of all forms of discrimination, as well as all forms of violence against women and girls, including harmful traditional and customary practices, abuse, rape and other forms of sexual violence;
23. *Strongly urges* governments to coordinate efforts with and support the work of the United Nations, non-governmental organisations and other bodies or institutions involved in HIV/AIDS prevention in order to ensure that the human rights of individuals living with HIV/AIDS are upheld and protected;
24. *Calls on* all parliaments and governments to strengthen national mechanisms such as commissions, tribunals, legislation and coordinated strategies to protect, enforce and monitor, in their respective countries, the human rights of individuals infected with and affected by HIV/AIDS, and to eliminate all forms of stigma and discrimination, especially in respect of vulnerable groups such as women and children – both boys and girls – as they bear the brunt of the epidemic and are most likely to care for sick people and to lose jobs, family members, income and schooling opportunities as a result of the illness, and to pay equal attention to other vulnerable groups, such as prisoners;
25. *Urges* parliaments and governments to design HIV/AIDS policies and programmes that effectively recognise the needs of women in particular, and that are sensitive to differences in terms of culture and religion that may exist in societies;
26. *Further urges* parliaments and governments to consider the public health safeguards provided for by the 30 August 2003 decision of the General Council of the WTO allowing members to produce and/or export pharmaceutical products needed to combat infectious diseases such as HIV/AIDS that threaten societies, and to incorporate permitted flexibilities into national laws enacted in compliance with the WTO TRIPS Agreement;
27. *Calls upon* parliaments and governments to ban compulsory HIV/AIDS screening for people applying for travel visas, university enrolment, jobs, or asylum, in favour of voluntary testing;

28. *Further calls* for special attention to be given to preventing HIV/AIDS by disseminating adequate and target group-oriented information, using all available media and multipliers, raising awareness and educating both men and women, with particular attention paid to adolescent boys and girls; and requests the inclusion of sex education in school curricula, for both boys and girls, as a means of prevention;
29. *Urges* the national and local agencies concerned to give high priority to assisting pregnant and breastfeeding women suffering from HIV/AIDS in order to protect their babies from infection;
30. *Requests* parliaments and governments to establish coordinated, participatory, transparent and accountable national policies and programmes for HIV/AIDS response, and to translate these national policies into action at the district and local levels, wherever possible involving, in development and implementation, non-governmental and community-based organisations, religious organisations, the private sector, and more importantly, people living with HIV/AIDS, and particularly the most vulnerable among them, including women and children;
31. *Calls upon* men and women parliamentarians to ensure that national budgets are gender-sensitive, thereby efficiently addressing the needs of both men and women;
32. *Calls for* the enhancement of support and resources for UNAIDS, and for increased financial contributions for the Global Fund to Fight AIDS, Tuberculosis and Malaria;
33. *Urges* parliaments and governments to promote international cooperation, growth and development as steps towards the containment of conflict situations and the reduction of their possible impact on HIV/AIDS;
34. *Urges* States, in conformity with United Nations Security Council resolution 1325 (2000) on women, peace and security, to ensure adequate HIV/AIDS awareness training for members of the military and the police, and for peace-keeping personnel;
35. *Reiterates* its call to governments to recognise the International Partnership against AIDS in Africa and to promote it, along with the Global Fund to Fight AIDS, Tuberculosis and Malaria, as the framework for action to fight AIDS in Africa;
36. *Affirms* the importance of narrowing the economic and cultural gap between the developed and developing countries, while ensuring that the strategies and programmes employed in the fight against HIV/AIDS take into consideration the natural, human and cultural characteristics of the regions where they are applied, so as to reflect both the characteristics of the demographic structure of each region and the social and economic conditions of its inhabitants;
37. *Emphasises* that countries should integrate the development of public health undertakings into their national economic and social development strategies, which should include the establishment and improvement of effective public health mechanisms, in particular a network for the supervision, prevention, and treatment of the HIV/AIDS epidemic, and for the exchange of information.

Annex 4

Key partners in the response to AIDS

Civil society

Civil society partners in the response to AIDS include:

- people living with and affected by HIV, and their associations and organizations;
- NGOs currently or potentially working on HIV-related issues, as well as international NGOs in fields such as development, human rights, education and health, that are contributing – or could contribute – to preventing HIV infection and reducing the impact of the epidemic on individuals, families and communities;
- faith-based organizations;
- employers' organizations and trade unions.

The private sector is also a major non-State actor but not always identified as part of civil society.

The involvement of civil society has been of crucial importance in dealing with HIV. An effective response to the HIV epidemic requires a partnership approach whereby governmental agencies, parliamentarians, communities, NGOs and groups affected by HIV – especially people living with HIV – are involved.

The following is a list of key civil society organizations with a global mandate. Many of these organizations have regional and national members and affiliates that can be accessed via their web sites.

➔➔ *For additional information about HIV services worldwide, see the listing of over 3300 HIV organizations in 175 countries available via www.aidsmap.com.*

Networks of people living with HIV

Global Network of People Living with HIV/AIDS (GNP+):

www.gnpplus.net

International Community of Women Living with HIV/AIDS (ICW):

www.icw.org

Networks and coalitions representing the interests of most-at-risk populations

HIV treatment activists

International Treatment Preparedness Coalition (ITPC):
www.aidstreatmentaccess.org

Youth

Global Youth Coalition on HIV/AIDS: www.youthaidscoalition.org
Youth Coalition: www.youthcoalition.org

Women

Women's Coalition: Women Won't Wait: www.womenwontwait.org
The Global Coalition on Women and AIDS: womenandaids.unaids.org

Men who have sex with men

The Global Forum on MSM & HIV: www.msmandhiv.org/

People who use drugs

International Harm Reduction Association:
www.ihra.net/HarmReductionNetworks

Sex workers

Network of Sex Work Projects: www.nswp.org

AIDS service organizations

International Council of AIDS Service Organizations: www.icaso.org

AIDS campaigners

World AIDS Campaign: www.worldaidscampaign.info

Faith groups and faith-based organizations

Interfaith

African Network of Religious Leaders Living with and Personally Affected by HIV and AIDS (ANERELA+): www.anerela.org (ANERELA+ is in the process of developing an international network – ANERELA+)

World Conference of Religions for Peace: www.religionsforpeace.org

Asian Interfaith Network on AIDS: www.asiaina.org

Christian/ecumenical

Ecumenical Advocacy Alliance (EAA): www.e-alliance.ch

World Council of Churches, Ecumenical HIV and AIDS Initiative in Africa:
www.oikoumene.org/en/programmes/justice-diakonia-and-responsibility-for-creation/hivaids-initiative-in-africa-ehaia.html

Islamic

Islamic Relief: www.islamic-relief.com

Positive Muslims: www.positivemuslims.org.za

Buddhist

Sangha Metta Project: www.buddhanet.net/sangha-metta/project.html

Jewish

American Jewish World Service: www.ajws.org

The Jerusalem AIDS Project: www.aidsnews.org.il

Hindu

Shakti Ashram: www.shantiashram.org

Labour/trade unions

Global Unions Programme on AIDS: www.global-unions.org/hiv-aids

Business

Global Business Coalition on HIV/AIDS, Tuberculosis and Malaria:
www.businessfightsaids.org

Media

Global Media AIDS Initiative: www.thegmai.org

UNAIDS and its Cosponsors**Joint United Nations Programme on HIV/AIDS (UNAIDS)**

UNAIDS, the Joint United Nations Programme on HIV/AIDS, brings together the efforts and resources of 10 UN system organizations to the global response to HIV, along with the UNAIDS Secretariat.

Cosponsors include UNHCR, UNICEF, WFP, UNDP, UNFPA, UNODC, ILO, UNESCO, WHO and the World Bank. Based in Geneva, the UNAIDS Secretariat works on the ground in more than 75 countries worldwide.

Under the UNAIDS umbrella, the 10 Cosponsors work with each other and with national governments, donors, nongovernmental organizations and other stakeholders to strengthen and implement country-led responses to the AIDS epidemic.

➔ *For more detailed information about the activities of UNAIDS and the 10 Cosponsors, see: UNAIDS at country level. Supporting countries as they move towards universal access. Geneva: UNAIDS, 2007. Available via www.unaids.org.*

Office of the United Nations High Commissioner for Refugees (UNHCR)

Under the UNAIDS division of labour, UNHCR is responsible for addressing HIV among displaced populations (refugees and internally displaced persons).

UNHCR's objectives are to combat HIV among refugees, internally displaced populations, returnees and other persons of concern as well as to ensure that the human rights of persons of concern to UNHCR who are living with HIV are duly respected. The organization's work is focused on protection, rights-based advocacy, prevention, treatment, care, support, training and capacity-building.

For more information: www.unhcr.org

United Nations Children's Fund (UNICEF)

Under the division of labour agreed upon by all Cosponsors within UNAIDS, UNICEF is responsible for:

- care and support for people living with HIV, orphans and vulnerable children, and affected households;
- prevention of mother-to-child transmission (jointly with WHO);
- procurement and supply management, including training.

The UNICEF Medium Term Strategic Plan (MTSP) 2006–2009 identifies HIV as one of UNICEF's five core priorities.

For more information: www.unicef.org

World Food Programme (WFP)

Under the division of labour agreed upon by all Cosponsors within UNAIDS, WFP is responsible for dietary/nutrition support.

The main focus of WFP's HIV programmes is to provide nutritional support to care and treatment programmes, support orphans and children affected by HIV and link HIV education with school-feeding programmes, relief operations and other programmes. WFP places particular emphasis on addressing the needs and vulnerabilities of women and girls in its efforts to address the epidemic through food support and by promoting girls'

education. WFP also provides assistance to poor AIDS-affected households and individuals to meet their basic nutritional needs. WFP contributes food and nutritional support to HIV programmes in 51 countries.

For more information: www.wfp.org

United Nations Development Programme (UNDP)

UNDP is the largest development agency in the world. As a Cosponsor of UNAIDS, UNDP focuses on its leadership roles within the UNAIDS Division of Labour, addressing the human development, governance, human rights and gender dimensions of the epidemic. This includes promoting access to affordable AIDS pharmaceuticals through its work on trade and intellectual property issues, as well as helping to “make the money work” by serving as principal recipient for grants from the Global Fund to Fight AIDS, Tuberculosis and Malaria in over 25 countries, until national partners can administer these funds.

UNDP works in 166 countries to address development challenges and support the achievement of the Millennium Development Goals. Responding to the AIDS epidemic and fulfilling its role as a UNAIDS cosponsoring agency is one of the organization’s core priorities.

For more information: www.undp.org

United Nations Population Fund (UNFPA)

Under the division of labour agreed upon by all Cosponsors within UNAIDS, UNFPA is responsible for provision of information and education, condom programming, prevention for young people outside schools, and prevention efforts targeting vulnerable groups (except people who inject drugs, prisoners and refugee populations).

UNFPA works to intensify and scale up universal access to HIV prevention using rights-based, evidence-informed strategies, including strengthening linkages with sexual and reproductive health information and services, and attention to the gender inequalities that fuel the epidemic.

In line with the division of labour, the Fund takes a leadership role in comprehensive condom programming and prevention among young people and women. It also reaches out to other vulnerable populations, including sex workers and their clients.

For more information: www.unfpa.org

United Nations Office on Drugs and Crime (UNODC)

UNODC is the lead agency within the UNAIDS family for prevention and care of HIV among people who inject drugs and in prison settings. In addition, UNODC is also responsible for facilitating the development of a UN response to AIDS associated with human trafficking.

Towards that aim, UNODC assists countries in building national capacity to conduct situation assessments, develop and implement enabling policies and rapidly scale up effective HIV prevention and care programmes among people who inject drugs, in prison settings and among people vulnerable to human trafficking.

For more information: www.unodc.org

International Labour Organization (ILO)

As the tripartite UN agency that brings together governments, employers and workers of its Member States in common action to promote decent work throughout the world, the ILO's mandate is to promote social justice and internationally recognized human and labour rights. Under the division of labour agreed upon by all Cosponsors within UNAIDS, the ILO is responsible for policies and programmes to respond to the AIDS epidemic in the workplace, to mitigate its effects in the world of work, and to lower poverty through access to decent work, thereby reducing an important root cause of the epidemic. The Organization has developed a *Code of Practice on HIV/AIDS and the world of work* as the framework for action at national and enterprise levels, especially in addressing employment-related stigma and discrimination. The code rests on a body of international labour standards, fundamental principles and rights at work.

The ILO helps make the workplace a more effective entry point for universal access by:

- promoting and engaging in action to increase access to decent work, boost employment, improve conditions of work, and increase the levels of health and safety in the workplace;
- strengthening the capacity of its constituents (employers, workers and ministries of labour) to develop workplace policies and programmes and combat discrimination;
- integrating HIV in structures and programmes of occupational safety and health, vocational training, social security, and other relevant services in the workplace.

For more information: www.ilo.org, <http://www.ilo.org/public/english/protection/trav/aids/>

United Nations Educational, Scientific and Cultural Organization (UNESCO)

Under the division of labour agreed upon by all Cosponsors within UNAIDS, UNESCO is responsible for prevention for young people in education institutions. As such, UNESCO's response to AIDS focuses on both the role of education in reducing the spread of HIV, and on means to lessen the impact of AIDS on countries' education systems. To accomplish this and to promote the achievement of 'Education for All' and the Millennium Development Goals, UNESCO supports countries in implementing comprehensive education sector responses to AIDS, expanding the evidence base and disseminating good practice, and establishing normative guidance for, and promoting, quality education.

UNESCO also leads the UNAIDS Global Initiative on Education and HIV & AIDS (EDUCAIDS).

For more information: www.unesco.org/aids

World Health Organization (WHO)

The WHO is the world's leading global public health agency responsible for global health and for setting public health standards and norms. Under the division of labour agreed upon by all Cosponsors within UNAIDS, the WHO is responsible for:

- prevention of HIV transmission in health-care settings, blood transfusion safety, injection safety, counselling and testing, STI diagnosis and treatment, and linkage of HIV prevention with AIDS treatment services;
- antiretroviral treatment and monitoring, prophylaxis and treatment for opportunistic infections (adults and children);
- establishment and implementation of surveillance for HIV, through sentinel/population-based surveys;
- prevention of mother-to-child transmission (jointly with UNICEF).

For more information: www.who.int/hiv

The World Bank

Under the division of labour agreed upon by all Cosponsors within UNAIDS, the World Bank is responsible for supporting countries in strengthening their national AIDS strategies and annual action plans, ensuring they are prioritized, costed and evidence-based. The World Bank hosts the AIDS Strategy and Action Plan (ASAP) service on behalf of UNAIDS.

In response to country needs, emerging and long-standing challenges to an effective response to AIDS, lessons and experience and its comparative

advantage, the World Bank developed its Global HIV/AIDS Program of Action in 2005. The Program of Action lays out a prioritized program for the next three years to strengthen Bank support for more effective national AIDS responses, working closely with major partners. The Program of Action builds on existing Bank regional strategies or business plans. There are five integrated key action areas in the Program of Action:

- continued and *sustained funding* for national and regional AIDS programs, especially to fill gaps, to strengthen health systems, and to support effective national AIDS responses that are of sufficient scale and scope to make a difference on the ground
- support for *strengthening national AIDS strategies and annual action plans*, to ensure they are truly prioritized, evidence-based, integrated into development planning and can be implemented
- *accelerating implementation*, to increase the scope and quality of priority activities
- strengthening *country monitoring and evaluation systems* and evidence-informed responses, to enable countries to assess and improve their programs
- *knowledge generation and impact evaluation* of what works, as well as other analytical work to improve program performance.

The World Bank contributes to universal access to HIV prevention, care and treatment through funding for comprehensive AIDS programs in all regions and countries where the Bank finances HIV-related projects and programs as well as through ensuring that HIV is part of the broader development agenda.

For more information: www.worldbank.org

Endnotes

- 1 UNAIDS/IPU (1999). *Handbook for legislators on HIV/AIDS, law and human rights*. Geneva.
- 2 United Nations (2006). *Political declaration on HIV/AIDS*. United Nations General Assembly, 60th session, 2 June 2006. New York.
- 3 Piot P (2006). AIDS: from crisis management to sustained strategic response. *Lancet*, 368:526–30.
- 4 The Security Council adopted resolution 1308, stating that “the HIV/AIDS pandemic, if unchecked, may pose a risk to stability and security.” The full text of resolution 1308 can be accessed via <http://www.un.org/Docs/scres/2000/sc2000.htm>.
- 5 United Nations Development Programme (2005). *Human development report 2005*. New York. Available at http://hdr.undp.org/reports/global/2005/pdf/HDR05_complete.pdf.
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It also cooperates with the regional interparliamentary organizations as well as with international, intergovernmental and nongovernmental organizations that are motivated by the same ideals.

The Joint United Nations Programme on HIV/AIDS (UNAIDS)

UNAIDS, the Joint United Nations Programme on HIV/AIDS, is an innovative joint venture of the United Nations family, bringing together the efforts and resources of 10 UN system organizations in the AIDS response to help the world prevent new HIV infections, care for people living with HIV, and mitigate the impact of the epidemic. Cosponsors include UNHCR, UNICEF, WFP, UNDP, UNFPA, UNODC, ILO, UNESCO, WHO and the World Bank. With its headquarters in Geneva, Switzerland, the UNAIDS Secretariat works

on the ground in more than 75 countries worldwide. Coherent action on AIDS by the UN system is coordinated in countries through the UN theme groups, and the joint programmes on AIDS.

UNAIDS helps mount and support an expanded response to AIDS – one that engages the efforts of many partners from government, civil society, the private sector and others.

UNDP

UNDP is the largest development agency in the world. As a Cosponsor of UNAIDS, UNDP focuses on its leadership roles within the UNAIDS division of labour, addressing the human development, governance, human rights and gender dimensions of the epidemic. This includes promoting access to affordable HIV pharmaceuticals through its work on trade and intellectual property issues, as well as helping to ‘make the money work’ by serving as principal recipient for grants from the Global Fund to Fight AIDS, Tuberculosis and Malaria in over 25 countries, until national partners can administer these funds.

UNDP works in 166 countries to address development challenges and support the achievement of the Millennium Development Goals. Responding to the AIDS epidemic and fulfilling its role as a UNAIDS Cosponsoring agency is one of the organization’s core priorities.

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