

# Handbook for Legislators on HIV/AIDS, Law and Human Rights

Action to Combat HIV/AIDS in View of its  
Devastating Human, Economic and Social Impact



Joint United Nations Programme on HIV/AIDS

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# **Handbook for Legislators on HIV/AIDS, Law and Human Rights:**

**Action to Combat HIV/AIDS in View of its  
Devastating Human, Economic and Social Impact**

**UNAIDS / IPU  
Geneva, Switzerland  
1999**

## Foreword

As the 20th century draws to a close, HIV and AIDS continue to wreak havoc on an ever-increasing number of individuals, couples, families, and communities. More than 90 percent of the 33.6 million people living with HIV/AIDS at the end of 1999 were in the developing world. In many developing countries, the epidemic has come to represent a threat to human security itself. Sparing neither children nor parents, neither teachers, health workers, farmers, nor other active members of society, AIDS is wiping out gains in social and economic development.

Every year, leaders who previously were confident that their own peoples were somehow immune from HIV for reasons of culture, religion or geography find their countries hard-hit by the epidemic. Politicians in some countries have ignored the threat of AIDS, perhaps for fear that discussions about safer sex, reducing harm to injecting drug users or other sensitive subjects would alienate one or another segment of their supporters.

In other places, however, political leaders have courageously taken on the epidemic, placing themselves in the vanguard of those battling to beat back HIV/AIDS in the most effective ways possible. The greatest achievements in preventing the spread of HIV and alleviating the impact of AIDS have been in countries whose leaders have demonstrated strong political will and commitment.

The purpose of this *Handbook* is to assist parliamentarians and other elected officials in promulgating and enacting effective legislation and undertaking appropriate law reform in the fight against AIDS. Whether it be constitutional amendments to prohibit discrimination against people living with HIV/AIDS or against those most vulnerable to infection, legislation to ensure the rights of school children to be educated on how to protect themselves as they grow older, to name only a few areas of concern, the full engagement of legislators is crucial to ensuring effective responses to the epidemic and adequate fiscal and other resources to support them.

The *Handbook* provides examples of best legislative and regulatory practices gathered from around the world. Best practices are given for each of the twelve guidelines contained in the *International Guidelines on HIV/AIDS and Human Rights* published in 1998 by the Office of the United Nations High Commissioner for Human Rights and the Joint United Nations Programme on HIV/AIDS (UNAIDS). The *Handbook* presents concrete measures that legislators can take to protect human rights and promote public health in responding to the epidemic.

The *Handbook* is the product of a growing partnership between the Inter-Parliamentary Union (IPU) and UNAIDS, which share a commitment to the

respect, protection and fulfilment of human rights as a value in itself, and as central to the achievement of their institutional goals and objectives.

We hope that parliamentarians and other elected officials around the world will be able to make use of this *Handbook* in advancing their national and community responses to AIDS, and we urge them to declare or renew their political commitments to preventing the spread and alleviating the impact of this terrible epidemic.



*Peter Piot*  
Executive Director  
Joint United Nations Programme  
on HIV/AIDS



*Anders Johnsson*  
Secretary-General  
Inter-Parliamentary Union

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Dr Carolyn Bennett  
Canadian IPU Group  
40 Elgin, Suite 1033  
Ottawa, Ontario K1A 0A4  
Canada

Mr David Borrow  
House of Commons  
London SW1A 0AA  
United Kingdom

Mr Victor Chernykh  
Noviy Arbat, 19  
Moscow  
Russian Federation

Mr Alexandre Waota Coulibaly  
Assemblée Nationale de Côte d'Ivoire  
Boîte postale 01 B.P. 1 381  
Abidjan 01  
Côte d'Ivoire

Mr Juan M. Flavier, Senator  
c/o Inter Parliamentary Relations and Protocol Service  
Senate of the Republic of the Philippines  
Room 604, GSIS Headquarters, Roxas Blvd.  
Pasay City  
Philippines

Mme Catherine Génisson  
Palais Bourbon  
75355 Paris 07 SP  
France

Dr Paul Günter  
Délégation suisse auprès de l'Union interparlementaire  
3003 Berne  
Switzerland

Dr (Smt.) Najma Heptulla  
President of the Council of the Inter-Parliamentary Union  
4, Akbar Road  
New Delhi  
India

Mr Essop Essack Jassat  
All Party Parliamentarian Group on AIDS  
Portfolio Committee on Health  
National Assembly  
Cape Town 8000  
South Africa

Mr O.M. Kgospula  
National Assembly  
P.O. Box 240  
Gaborone  
Botswana

Dr Newton Kulundu  
c/o Secretary/Treasurer  
IPU Kenya Group  
National Assembly  
Parliament Buildings  
P.O. Box 41842  
Nairobi  
Kenya

Ms Zury Ríos Montt  
2<sup>a</sup> calle A 13-77 zona 15  
Colonia Tecún-Umán  
Guatemala City  
Guatemala

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## ACRONYMS

<b>ACCSI</b>	Citizens Action Against AIDS
<b>APPGA</b>	All-Party Parliamentary Group on AIDS
<b>ASO</b>	AIDS service organization
<b>BEMFAM</b>	Societade Civil Bem-estar Familiar do Brasil
<b>CBO</b>	Community-based organization
<b>CDC</b>	Centers for Disease Control and Prevention
<b>CI</b>	Caritas Internationalis
<b>CIDE</b>	Centro de Informacion y Desarrollo de la Mujer
<b>CIOMS</b>	Council for International Organizations for Medical Services
<b>DFID</b>	Department for International Development
<b>HREOR</b>	Human Rights and Equal Opportunity Commission
<b>IAVI</b>	International AIDS Vaccine Initiative
<b>ICASO</b>	International Council of AIDS Service Organizations
<b>IPU</b>	Inter-Parliamentary Union
<b>LACCASO</b>	Latin American and Caribbean Council of AIDS Service Organizations
<b>MAP</b>	Monitoring the AIDS Pandemic (MAP) Network
<b>MTV</b>	Music Television International
<b>NEP</b>	Needle exchange programme
<b>NGO</b>	Nongovernmental organization
<b>PLWHA</b>	Persons Living with HIV/AIDS
<b>PNAC</b>	Philippines National AIDS Council
<b>SAARC</b>	South Asian Association for Regional Cooperation
<b>SADC</b>	Southern Africa Development Community
<b>SAR</b>	Special Administrative Region of China
<b>TASO</b>	The AIDS Support Organization
<b>THT</b>	Terrence Higgins Trust
<b>UNDAW</b>	United Nations Division for Advancement of Women
<b>UNDCP</b>	United Nations International Drug Control Programme
<b>UNDP</b>	United Nations Development Programme
<b>UNESCO</b>	United Nations Educational, Scientific and Cultural Organization
<b>UNFPA</b>	United Nations Fund for Population Activities
<b>UNICEF</b>	United Nations Children's Fund
<b>USAID</b>	United States Agency for International Development

# EXECUTIVE SUMMARY

The Introduction to this report sets out the shocking statistics of the epidemic – 33.4 million people are currently living with HIV/AIDS. An effective response is required to avert the devastation wreaked on communities around the world by the epidemic. This impact is disproportionately felt in developing countries and vulnerable populations (those whose human rights are already not fully respected).

The Background highlights important features of the Inter-Parliamentary Union (IPU) Windhoek Resolution (1998). It gives examples of political leaders who have made supportive public statements, and regional/national initiatives by parliamentarians who have made the HIV/AIDS and human rights connection.

A brief outline is given of the international law basis of the *International Guidelines on HIV/AIDS and Human Rights*. These Guidelines require States Parties to human rights treaties to review, and if necessary amend, their laws, policies and practices to ensure compliance with defined norms. Certain rights, including health, nondiscrimination, privacy, education, information, autonomy, liberty, freedom of expression and association, and freedom from inhuman, degrading treatment or punishment are then examined specifically in the context of HIV/AIDS.

The Handbook analyses each of the 12 International Guidelines on HIV/AIDS and Human Rights and gives best practice examples of their implementation, in terms of content and/or process, at national and sometimes local and regional levels.

## (A) Institutional Responsibilities and Processes

### **Guideline 1 – National framework** (pages 30-34)

The Handbook identifies several ways in which policies and programmes can be integrated in all relevant branches and levels of government.

#### (1) Interministerial committees

Relevant portfolios (health, education, justice, welfare, housing, transport, tourism etc.) should be included in such bodies and Cabinet subcommittees to ensure coordination at high level of HIV/AIDS strategies. Examples are given of such bodies in several countries, including one chaired by the Thai Prime Minister.

**(2) Parliamentary committees on HIV/AIDS**

Special legislative committees were recommended in the Namibian resolution to provide a nonpartisan forum for parliamentarians to deepen their understanding of HIV/AIDS issues and promote consensus. The UK All-Party Parliamentary Group on AIDS is a good example of such a committee.

**(3) Multisectoral advisory bodies**

Professional and community representation is essential on bodies advising the government on general issues (e.g. the Malaysian AIDS Council), and especially those addressing legal and ethical issues (e.g. committees in South Africa and Canada).

**Guideline 2 – Supporting community partnership** (pages 34-36)

The partnership approach in all stages of policy design, programme implementation and evaluation was explicitly endorsed by the Windhoek Resolution. Representation on advisory committees is one mechanism to implement this Guideline. The Handbook gives the example of several successful NGOs, such as TASO in Uganda.

**(B) Law Review, Reform and Support Services**

This section is the most weighty and technical part of the Handbook. Legislative checklists are included in the text in ten areas to assist with implementation. The actual process of law reform on HIV/AIDS and human rights is very important. The Handbook gives best practice examples of how this has been achieved in several countries, including the Philippines *AIDS Prevention and Control Act 1998*.

**Guideline 3 – Public health legislation** (pages 36-49)

The Handbook highlights the recognition of public health as a government responsibility, and its reflection in laws mandating the provision of prevention, treatment and care services. Unfortunately some old infectious diseases laws were automatically extended to HIV/AIDS with absurdly inappropriate results, such as prohibiting persons living with HIV/AIDS from using public transport or working in certain industries.

**(1) Testing**

The need for specific informed consent with counselling before and after testing is analysed. Mechanisms that are consistent with this objective are discussed – such as laboratory request forms being given legislative force by inclusion in public health regulations. Public policy reasons for not obliging testing of targeted populations are also set out.

**(2) Notification/Partner notification**

The need to collect data for public health reasons is acknowledged, but privacy protections are suggested, such as the use of coded data for notifying health authorities of new cases of HIV infection. Protocols for notifying sexual partners of HIV-infected persons without their consent in special circumstances are also discussed.

### (3) Detention

The lack of public health justification for isolating people solely on the basis of their HIV status is emphasized. Where liberty is restricted it should be on the basis of behaviour in exceptional cases and with due process protections.

### (4) Blood safety

The Handbook highlights the urgency of ensuring a safe blood supply run by an accountable national service, with voluntary donors and HIV screening. Successful case studies are given of Uganda and Zimbabwe.

### (5) Universal precautions

The need for infection control in health care and other settings involving exposure to blood and body fluids is essential. Detailed requirements are codified under public health legislation in some jurisdictions, such as in the USA.

## **Guideline 4 – Criminal laws and correctional systems** (pages 50-63)

This is an area of the law where repressive legislation can impede prevention programmes by making HIV/AIDS educators liable for aiding or abetting criminal offences.

### (1) Transmission/exposure offences

Such laws are common (part of being seen as being “tough” on crime), but they are not recommended and should only be used as a last resort. If enacted they should be generic rather than HIV-specific, and have appropriate defences such as for consent and use of protective measures (e.g. condoms). Protocols between law enforcement and public health authorities are essential, so that inappropriate cases are not brought before the courts without scientific information.

### (2) Needle and syringe exchanges

Needle and syringe exchange programmes are part of a harm-reduction approach and have been very successful in limiting the spread of the virus in injecting drug users. Several case studies are given, including that of an NGO in St Petersburg.

### (3) Sexual acts

Private sexual acts such as adultery, sodomy and fornication are prohibited in some countries in order to attempt to protect public morality. Public health requires that these laws be repealed, otherwise risk behaviour is driven underground.

### (4) Sex work (prostitution)

Public health objectives are much more likely to be achieved by regulating sex work as a personal service industry, focusing on management by mandating universal precautions (e.g. condoms). Many case studies have been documented, including Sonagachi in Calcutta.

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### (5) Prisons

HIV prevalence is soaring in prisons because of unsafe behaviour. Education and information interventions, such as those in Brazil, have been successful, unlike crude repression. Lack of such programmes condemn prisoners, and the communities they later return to to HIV infection.

### **Guideline 5 - Antidiscrimination and protective laws** (pages 64-78)

#### (1) Antidiscrimination legislation

The Handbook refers to the chilling case of an NGO volunteer killed by a mob in South Africa just after she made a personal testimony about her HIV status on World AIDS Day. Antidiscrimination laws are common in many countries, such as Canada, France, South Africa, and the United Kingdom. Administrative agencies, like human rights commissions, usually investigate and conciliate complaints of discrimination on many grounds, with HIV/AIDS often being included as a disability.

#### (2) Discriminatory impact on vulnerable populations

Laws can be the source of systematic discrimination against women, young people and gay men by not protecting them against sexual violence, unfair property laws, and failing to recognize domestic relationships (e.g. de facto relationships, irrespective of sexuality).

#### (3) Privacy

The sensitivity of HIV-related information exists because of the stigma surrounding the epidemic. Laws protecting privacy are common in Western Europe and Canada, with medical data often being given special protection. Administrative agencies, such as privacy commissioners, usually operate like human rights commissions.

#### (4) Employment law

Protection is needed in respect of coerced testing and unfair discrimination in the workplace. The impact is magnified where people are infected in their prime productive ages, but are dismissed, despite their ability to work for a long time (particularly with the availability of antiretroviral treatments). The Worksafe Australia Code of Practice for Health Care Workers is cited as a best practice case study of occupation health and safety standards.

### **Guideline 6 – Regulation of goods, services and information** (pages 79-87)

#### (1) Therapeutic goods legislation

Such laws safeguard the standard and availability of items such as testing kits, condoms and medicines. The Handbook refers to the success in France in 1987 of lifting barriers to the distribution of condoms.

**(2) Ethical research**

The need for the protection of human participants in HIV-related research is vital. The Handbook outlines the operation of ethical review committees, and gives case studies on vaccine development in Brazil, Thailand and Uganda. Initiatives for improving access to treatment in several countries are described.

**(3) Education and information**

Explicit material is essential, but broadcasting standards can be a barrier to general media and targeted campaigns unless there are exemptions for educational materials.

**(4) Expression and association**

NGOS, especially those representing vulnerable populations, such as gay men, sex workers and injecting drug users, can be hampered by laws restricting their association – the reasons given by governments for refusing registration can either be their illegal behaviour, or the fact that they are critical of government inaction.

**Guideline 7 – Legal support services** (pages 88-89)

Best practice case studies of services that go beyond law reform, by helping people actually enforce their rights are described. Examples are given from countries including Venezuela.

**(C) ENABLING ENVIRONMENT****Guideline 8 – Women, children and other vulnerable populations** (pages 90-97)

Improving the social and legal status of populations whose human rights are not fully respected is a huge, but necessary, undertaking. Vulnerability depends on the legal, social and economic conditions, as well as the nature of the epidemic in each country. The groups most commonly affected are women, children, religious or ethnic minorities, indigenous people, migrants, refugees, internally displaced persons, people with disabilities, economically disadvantaged groups, itinerant workers, gay men, injecting drug users and sex workers. Targeted programmes in three main areas are considered.

**(1) Gender**

Projects that improve the literacy, education and financial situation of women exist in many countries, such as Nepal. Important reforms have occurred in many countries at the institutional level, e.g. Offices or Ministries of Women's Affairs, and through legislation, e.g. prohibiting female genital mutilation. The need to include men in projects wishing to influence gender relations is emphasized.

**(2) Young people**

More than half of people living with HIV/AIDS (PLWHA) were infected before they were 25 years of age. By 2010 UNAIDS expects that there will be 40 million children orphaned by AIDS. Factors increasing vulnerability of young people include poverty,

## EXECUTIVE SUMMARY

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violence, lack of skills, and harmful social norms relating to sexual relationships. Projects working with young people to equip them with necessary knowledge, life skills and services are explored in various settings e.g. peer education in Zambia, and street children in Brazil.

### (3) Religious minorities

A best practice case study is given of a prevention and education project with the minority Muslim population in Uganda.

### **Guideline 9 – Changing discriminatory attitudes through education, training and the media** (pages 98-100)

Changing discriminatory attitudes requires more than legislation. The public activities of people like the late Princess Diana of Wales went a long way in trying to achieve this. Public statements by parliamentarians are also a powerful force to address prejudice. Funded media campaigns by governments, such as the one from Australia, which is described, are also influential.

### **Guideline 10 – Development of public and private sector standards and mechanisms for implementing these standards** (pages 100-101)

The Handbook gives examples of innovative public-private sector partnerships to respond effectively to the epidemic. The HIV/AIDS Employment Code of Conduct of the Southern African Development Community is a best practice example. Other relevant areas include health care and the media.

### **Guideline 11 – State monitoring and enforcement of human rights** (pages 101-103)

The Handbook outlines the Paris Principles on national human rights institutions that emphasize the need for human rights commissions to be independent, accessible and accountable. Examples of human rights commissions in Uganda and India are given.

### **Guideline 12 – International cooperation** (pages 103-107)

#### (1) Compliance mechanisms

UNAIDS activities impacting on organizations, such as the UN bodies set up under human rights treaties, are set out.

#### (2) NGO mobilization

Integrating HIV/AIDS in the work of human rights NGOs and sensitizing AIDS service organizations to human rights are essential activities.

#### (3) Religious leaders

Strengthening links with religious bodies that have been involved in treatment and care from the beginning of the epidemic is a vital activity for many reasons. The example of Caritas Internationalis is described.



## ANNEXES

The first annex sets out medical facts about HIV/AIDS and recent initiatives in vaccine development and improving access to treatment, especially in developing countries. The second and third annexes include the IPU Windhoek Resolution and the International Guidelines on HIV/AIDS for reference purposes. The fourth and fifth annexes provide brief descriptions of the partners responsible for the development of this Handbook: UNAIDS and the IPU.

# I. INTRODUCTION

## (i) Gravity of the Global Problem

At the end of 1998 UNAIDS and WHO estimated that 33.4 million people were currently living with HIV infection, including 13.8 million women (43%) and 1.2 million children.<sup>1</sup> Most of these people do not even know that they are infected. The vast majority of people living with HIV/AIDS are in developing countries – 22.5 million people in sub-Saharan Africa (50 % of whom are women), 6.7 million people in south and south-east Asia, and 1.4 million people in Latin America. Annex A sets out medical facts and recent initiatives relevant to HIV/AIDS.

An estimated 2.5 million people died of AIDS in 1998, including 900,000 women and 510,000 children. Of the 47.3 million people who have been infected since the epidemic began two decades ago, nearly 14 million have already died. 95% of these deaths occurred in developing countries. During 1998, 6 million people were newly infected with HIV – this equates to 16,000 people being infected every day, a 10% increase on the previous year. Nearly half these new cases were in young people under the age of 24 years. If this trend continues, it is estimated that more than 40 million people will be infected with HIV by the year 2000. Governments, particularly those in developing countries where the epidemic is mainly focused, cannot ignore these statistics – early and effective interventions can save millions of lives and vitally affect the quality of life of those already infected with HIV.

## (ii) Impact on Development

Successful public health measures have stabilized the epidemic in most developed countries, but this is true of only some developing countries. Many developing countries are experiencing exponential growth of HIV/AIDS cases. Global spending on HIV/AIDS care, research and prevention reflects this disparity – developing countries only receive about 12% of such resources despite having 95% of cases. Socioeconomic factors contributing to the spread of HIV/AIDS which disproportionately impact on developing countries include: poverty; illiteracy; gender inequality; increased mobility of populations within and between countries; and rapid industrialization involving the movement of workers from villages to cities, and consequent breakdown of traditional values.<sup>2</sup>

Because HIV/AIDS is concentrated in prime-age adults who are usually at the peak of their economic productivity and are often heads of families, it has an immense impact

## I. INTRODUCTION

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on life expectancy, exacerbates inequality (e.g. surviving orphans), and increases the burden on health systems. Governance, development and human rights are increasingly being recognized as interdependent,<sup>3</sup> as HIV/AIDS undermines recent development achievements. In a few years of accelerated spread, AIDS has become the leading cause of adult death in some developing countries, and may be the most important macro-economic and social determinant of human welfare and poverty.<sup>4</sup> The risk of development projects worsening the epidemic in areas of high prevalence can be averted by effective government responses. An example is the Chad-Cameroon oil pipeline supported by the World Bank that has incorporated HIV/AIDS prevention interventions<sup>5</sup>.

### (iii) Purpose of this Handbook

The objective of this Handbook is to assist legislators to take action and make 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. Detailed and practical guidance on HIV-related law and policy reform is provided. The Handbook gives practical examples of implementation of the *International Guidelines on HIV/AIDS and Human Rights* from around the world. There has been a tendency on the part of some governments to make simple or ad hoc legislative reform without community consultation or proper consideration of human rights issues. Although the focus of the Handbook is on legal issues, other complementary methods of administrative implementation of human rights norms are encouraged, such as policy development and intergovernmental cooperation. Legal guarantees of rights may not be appropriate where rights cannot easily be tested in a court of law. Legislation would not be an effective means of practical implementation of human rights in some circumstances and countries, because of the lack of social or economic structures and resources that are a precondition to their fulfilment. Law is only one of a range of tools, including education, whereby social change conducive to containing the epidemic can be fostered.

Laws that prohibit private consensual behaviour that may transmit HIV can hasten the spread of the epidemic by acting as impediments to education, prevention and care programmes. The *WHO Directory of Legal Instruments Dealing with HIV/AIDS*<sup>6</sup> contains many examples of such laws enacted hastily by politicians keen to be seen to be taking tough action against AIDS. This Handbook is intended to help legislators and other policy-makers develop laws that are consistent with public health and human rights principles. It does not provide model laws at this time owing to the wide variety of legal systems in different countries. Diverse and innovative responses to the epidemic are encouraged where they comply with international human rights norms. The Handbook identifies best practice<sup>7</sup> examples from this rich resource of varying economic, social, and cultural values, traditions and practices around the world. Mainly positive case studies are described and analysed to show how compliance can be achieved. Occasionally, negative examples are used to show why and how some ineffective measures did not work, and what stimulated change or their abandonment.

## II. BACKGROUND

### (i) Windhoek IPU Resolution on HIV/AIDS

The Resolution adopted by the 99th Inter-Parliamentary Union (IPU) Conference in Windhoek, Namibia, is set out in Annex B. It highlights the need for joint action by the international community and organizations because of the impact of the epidemic on world economic development and social and political stability. The Resolution urges parliamentarians to demonstrate their political commitment to an effective response to the epidemic through intensifying their legislative, budgetary and oversight functions. Some of the specific recommendations are:

- taking a partnership approach by involving the widest possible range of concerned stakeholders, including people living with HIV/AIDS and the community, in decision-making processes, as well as information sharing;
- having targeted education and preventive measures as the key components of successful national AIDS strategies;
- establishing non-partisan parliamentary groups to ensure continuing dialogue, briefings and debate, as well as training activities, in order to deepen the understanding of the pandemic and promote a consensus on national policies;
- securing safe blood and blood product supplies;
- maintaining universal infection control precautions;
- establishing needle and syringe exchanges;
- developing an effective vaccine; and
- enabling equitable access to new treatments, particularly in developing countries that are disproportionately affected by the epidemic.

The Resolution calls for the exercise of international solidarity in providing financial assistance and technical and social support, as well as development assistance earmarked for AIDS programmes in developing countries.

The Resolution calls attention to the need to put into practice the *International Guidelines on HIV/AIDS and Human Rights*, particularly those dealing with:

- public health legislation;

## II. BACKGROUND

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- criminal law and prison systems;
- antidiscrimination legislation;
- privacy, confidentiality and ethics, including in the conduct of scientific research; and
- public and private sector standards and mechanisms for implementing the guidelines.

On the basis of these Guidelines and the commitments States Parties have already undertaken under international human rights law, the Resolution requested UNAIDS, in cooperation with the IPU, to develop this Handbook and disseminate it as a reference tool for establishing appropriate legal standards. A draft of this Handbook was considered by a UNAIDS/IPU Working Group of parliamentarians from twelve different countries which met in Geneva in February 1999.

### **(ii) Issues for Parliamentarians**

Legislators and government policy-makers, because of their ultimate responsibility for designing and implementing HIV/AIDS policies, are the principal audience for which the *International Guidelines on HIV/AIDS and Human Rights* were aimed. Parliamentarians can advance HIV/AIDS and human rights issues generally at local, national and regional levels in several of their roles:

- as political leaders, they can influence public opinion, and can increase public knowledge of relevant issues;
- as legislators, they vote on acts of parliament and can ensure that legislation protects human rights, and advances effective prevention and care programmes;
- as advocates, they can mobilize the involvement of government, private sector and civil society to discharge their societal responsibilities in responding appropriately to the epidemic; and
- as resource mobilizers, they can allocate financial resources to support and enhance effective HIV/AIDS programmes that are consistent with human rights principles.

Parliamentarians can specifically assist with implementation of the International Guidelines through:

- 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 to key actors and devel-

oping action plans for monitoring and implementation of priority issues; and

- participating in consultative review and reform of the law, by drafting either government sponsored or private member's bills.

Processes are needed to ensure that all branches of government follow a human rights-based response to the epidemic, including the legislature. Democratically elected parliamentarians are in a unique position to influence public opinion and lead their constituents towards attitudes supportive of an effective national response to the epidemic. Political commitment is an essential ingredient to a rights-based response to HIV/AIDS and to the allocation of adequate resources to implement it. The US State Department recently described AIDS as an important foreign policy issue:

**"Critical to turning the tide is governmental acknowledgment and political commitment for national and international action...[P]olitical commitment at the highest level of national government makes the critical difference. Many governments remain slow to acknowledge and respond with appropriate measures... It takes strong leadership at the highest levels working with international institutions, other nations, and nongovernmental sectors to join the fight by sharing needed specialized skills in support of global interests to combat the AIDS pandemic."**<sup>8</sup>

Leaders of some of the most-affected nations in Africa have increasingly shown awareness and openness regarding HIV/AIDS issues:

- in Botswana President Festus G. Mogae announced in 1998 a government monthly allowance (means-tested) for people living with HIV;
- the then President Nelson Mandela of South Africa, Honorary President of the Global Business Council on HIV/AIDS launched in Edinburgh in October 1997, said:

**"Many people live with HIV and AIDS, and many are at risk of becoming infected. Yet the reality is that the rights which should protect them from the vulnerabilities which AIDS sufferers endure are not adequately respected. We need to confront that reality and speak out against it"**<sup>9</sup>.

- the then Deputy President Thabo Mbeki of South Africa launched a national public awareness campaign in October 1998. Many workers were given the day off work to listen to his televised speech, and flags flew at half-mast on government buildings<sup>10</sup>.

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In several countries HIV/AIDS issues are included in most or all speeches of top political leaders, e.g. the Presidents in Zambia<sup>11</sup> and Uganda. Individual leadership is an important mobilizing force in the following examples:

- US President Clinton called for the urgent development of an AIDS vaccine:

**“Only a truly effective, preventive HIV vaccine can limit and eventually eliminate the threat of AIDS... So let us set a new national goal for science in the age of biology. Today, let us commit ourselves to developing an AIDS vaccine within the next decade... [I]f the 21<sup>st</sup> century is to be the century of biology, let us make an AIDS vaccine its first great triumph”<sup>12</sup>;**

- the President of Guatemala has launched World AIDS Day for several years;
- the President of Uruguay, Julio Maria Sanguinetti, spoke on World AIDS Day 1998, and a huge red ribbon was wrapped around the Palace of Justice;
- the former Indian Prime Minister, Shri Atal Bihari Vajpayee, on 12 December 1998, appealed to parliamentarians to take up AIDS awareness as a priority in their constituencies<sup>13</sup>;
- the Philippines First Lady, Amelita M. Ramos, mobilized the private sector to build accommodation for People Living with HIV/AIDS.

### Examples of regional and national initiatives

Peer support for parliamentarians is a vital mechanism to develop effective national responses to HIV/AIDS that respect human rights. It is important for parliamentarians to be knowledgeable about HIV/AIDS and to be key partners in developing policies, programmes and legislation that advance effective prevention and care for people living with HIV/AIDS (PLWHA). It is encouraging that in the past decade there has been increasing participation of parliamentarians in special and general forums, usually with community representation to give an accurate picture of the human dimensions of the epidemic. Examples of regional forums include the following:

- The Standing Conference of European Parliamentarians on HIV/AIDS made a Final Declaration at its meeting in Barcelona in May 1995. It affirms the Conference’s desire to create a cooperative association of parliamentarians:

**“We pledge ourselves both to recruit our fellow Parliamentarians individually, and to work towards the affiliation of the relevant committees or study groups in our Parliaments... [W]e pledge ourselves to keep these issues**

alive in our own Parliaments and to urge their importance on our governments with a view to ensuring the best use of resources in care and treatment, the maximum efficiency of prevention and the necessary research base for continuing advance in both prophylaxis and towards cure.”

The Conference made a number of practical recommendations, including taking action on drug harm minimization programmes, commencing sex education in schools before the start of sexual activity, and excluding Value-Added Tax on the means of HIV prevention, especially condoms.

- At the Tenth International Conference on STD/AIDS in Africa, an Alliance of Mayors and Municipal Leaders was formed which issued the Abidjan Declaration on 9 December 1997. The Declaration states that the Alliance commits itself to search for solutions relevant to local needs and realities, in accordance with UN principles and national laws and regulations, in order to respond more effectively to the epidemic. The creation of the Alliance is:

**“to maximise commitment, participation, leadership, capacity and experience at community level in response to the challenge of the HIV/AIDS epidemic”.**

- The South Asian Association for Regional Cooperation (SAARC) Medical Parliamentarians held a meeting on Reproductive Health, STDs and HIV/AIDS in Kathmandu in May 1998 which made a Declaration on the Prevention and Control of HIV/AIDS. It called for parliamentarians to take a stronger advocacy role and for action at the regional, national, and community levels. Specific recommendations included the establishment of a Regional Forum of SAARC Parliamentarians and mechanisms to review and reform national laws and policies.

Examples of national initiatives include the following:

- The Inter-American Parliamentary Group on Population and Development held a regional conference in March 1997 of parliamentarians and the heads of national programmes on HIV/AIDS in Managua, Nicaragua. A seminar on HIV and human rights was held in the Nicaraguan Parliament while it was in session in March 1996. It was provided by the United Nations Development Programme (UNDP) HIV and Development Programme and included partners such as members of the Network on Ethics, Human Rights and Judicial Aspects of HIV, and the Latin America and Caribbean Council of AIDS Service Organizations (LACCASO). The special session was opened by the President of the National Assembly and closed by the Vice-President. The success of the seminar was demonstrated by the later enactment of Law No. 238 (Promotion, Protection and Defence of Human Rights in the face of AIDS)<sup>14</sup>.



- In Dhaka, Bangladesh, a successful workshop on HIV/AIDS and STDs was held in September-October 1997 for parliamentarians by ACTIONAID, a local NGO, and the government AIDS Prevention and Control Programme. It included a presentation by peer educators of sex workers at the Tangail brothel<sup>15</sup>. Legislators were given information kits before two one-day colloquiums – the first being general and the second for female members of parliament. The objectives were: to create an environment where participants felt at ease to talk; to bridge the gap between lawmakers and activists; to share prevention and management interventions; and to identify areas where lawmakers could contribute at policy level, in Parliament and in the local area they represent. The Minister for Health and Family Welfare, along with 21 other parliamentarians from various regions and major political parties, signed the Declaration of Social Commitment to work for the prevention of HIV/AIDS as lawmakers. Workshop participants agreed to participate in a special parliamentary committee to formulate policies, programmes, and implementation, monitoring and evaluation activities.

Similar initiatives have been held in countries such as India<sup>16</sup>, Nepal<sup>17</sup>, Mexico<sup>18</sup>, and Malawi<sup>19</sup>.

### **(iii) HIV/AIDS Law, Policy and Human Rights – International Guidelines**

Using the framework of human rights in an expanded response to the epidemic gives “real-world meaning beyond the realization of enumerated rights for their own sake”<sup>20</sup>. A rights-based prevention approach recognizes societal vulnerability to HIV/AIDS, not just individual risk behaviour. It also recognizes vulnerability in different contexts of stigmatized or disempowered populations, such as women, children, gay men, injecting drug users and sex workers. International human rights norms provide a coherent, normative framework for analysis of the HIV/AIDS problem. They also provide a legally binding foundation with procedural, institutional and other accountability mechanisms to address the societal basis of vulnerability and implement change<sup>21</sup>.

A lack of human rights protection fuels the epidemic in at least three ways:

- discrimination increases the impact of the epidemic on people living with HIV/AIDS and those presumed to be infected, as well as their families and associates. For example, a person who is sacked from his or her job because of being HIV-positive is faced with many problems, including the extra economic burdens of health care, as well as providing for any dependent family;
- people are more vulnerable to infection when their economic, social or cultural rights are not respected. For example, a refugee may be separated from former sources of support (such as family), and more likely to engage in activities which place his or her health at risk (such as unsafe sex); and

- where civil and political rights are not respected, and freedom of speech and association is curtailed, it is difficult or impossible for civil society to respond effectively to the epidemic. In some countries peer education is hampered by laws that refuse official registration to groups with certain memberships (for example, sex workers). In these cases, a meeting of an NGO or community-based organization with such a membership would be viewed as an illegal activity.

Public health and human rights are thus complementary, not conflicting, goals. The protection of public health should not be used as a pretext to justify punitive measures. Such measures may drive people most in need of prevention and care services underground, thereby blocking achievement of the desired goals of preventing new infections, and ensuring care and support for people living with HIV/AIDS. HIV/AIDS is not merely a medical problem – it requires a broader multifaceted response.

In September 1996, the Second International Consultation on HIV/AIDS and Human Rights was convened by UNAIDS and the Office of the UN High Commissioner for Human Rights. The consultation involved 35 experts from governments, voluntary bodies, AIDS service organizations, networks of people living with AIDS, judges, academics and regional bodies and agencies. The consultation developed *International Guidelines on HIV/AIDS and Human Rights*<sup>22</sup> that were welcomed in 1997 by resolutions of the Commission on Human Rights<sup>23</sup> and the Sub-Commission on the Prevention of Discrimination and Protection of Minorities<sup>24</sup>. In 1998 UNAIDS and the Office of the UN High Commissioner for Human Rights published the Guidelines in the six official UN languages, namely, Arabic, Chinese, English, French, Russian and Spanish<sup>25</sup>.

### Compliance with international obligations

The Guidelines provide explicit benchmarks to implement and measure performance in developing an effective rights-based response to the epidemic. The emphasis in the Guidelines is on governments as they are the responsible state parties under relevant international human rights instruments, but it is important to recognize that partnerships with other essential parts of society are crucial to an effective response to the epidemic. The Guidelines on HIV/AIDS and Human Rights clarify the obligations contained in existing human rights instruments, such as:

- the United Nations Charter;
- the Universal Declaration of Human Rights;
- the International Covenant on Economic, Social and Cultural Rights;

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- the International Covenant on Civil and Political Rights;
- the Convention on the Elimination of All Forms of Racial Discrimination;
- the Convention on the Elimination of All Forms of Discrimination Against Women;
- the Convention on the Rights of the Child;
- the Convention Against Torture, and Other Cruel, Inhuman or Degrading Treatment or Punishment; and
- various International Labour Organization conventions and recommendations.

As members of the United Nations, States are obliged to promote and encourage respect for human rights without discrimination under the UN Charter. Although the Universal Declaration is not a treaty as is the UN Charter, it is widely considered to be binding under customary international law<sup>26</sup>. The above-mentioned treaties are binding on States Parties that have signed and ratified them. Special UN machinery has been set up under many of these treaties in order to monitor State compliance through the obligation to furnish regular reports which are considered by the treaty committees in dialogue with individual States.

The Vienna Declaration and Programme of Action affirmed that human rights, whether civil, political, economic, social or cultural, are universal and indivisible<sup>27</sup>. States have a duty to respect, protect and fulfil these human rights and fundamental freedoms within their own political, economic and cultural systems. The obligation to respect rights requires states to abstain from interference with freedom of the individual; the obligation to protect rights requires states to prevent other individuals interfering with an individual's rights; and the obligation to fulfil rights requires states to take the measures necessary to ensure realization of the rights which cannot be secured by the personal efforts of the individual<sup>28</sup>.

It is important to note that in 1996 the UN Commission on Human Rights resolved that the term “or other status” used in several human rights instruments “should be interpreted to include health status, including HIV/AIDS” and that discrimination on the basis of actual or presumed HIV/AIDS status is prohibited<sup>29</sup>. The duty to fully realize human rights obligations can be approached in several ways. States are given some discretion in the actual manner of undertaking the realization of rights, as appropriate measures are not prescribed. Key human rights, with examples of their specific application in the HIV/AIDS context are:

- nondiscrimination and equality before the law, e.g. eliminating discrimination against people living with HIV/AIDS in the areas of health care, employment, education, immigration, international travel, housing and social security;

- health, e.g. ensuring equal and adequate access to the means of prevention, treatment and care, such as for vulnerable populations with lower social and legal status, (e.g. women and children);
- privacy, both informational and physical, e.g. ensuring confidentiality of HIV test results, and prohibiting mandatory or compulsory testing;
- education and information, e.g. ensuring equal and adequate access to prevention education and information, such as targeted material for ethnic minorities;
- freedom from inhuman, degrading treatment or punishment, e.g. prohibiting automatic isolation of HIV-positive prisoners;
- autonomy, liberty and security of the person, e.g. prohibiting HIV testing or research without informed consent, and prohibiting detention or quarantine solely on the basis of HIV status;
- sharing in scientific advancement and its benefits, e.g. ensuring equal and adequate access to a safe blood supply and universal infection control protocols or treatment drugs;
- work, e.g. prohibiting dismissal of staff solely on the basis of their HIV status;
- freedom of expression, assembly and association, e.g. ensuring availability of registration for groups of people living with HIV/AIDS, such as sex workers or men who have sex with men;
- participation in political and cultural life, e.g. ensuring the participation of persons living with HIV/AIDS in the formulation, implementation and evaluation of policy;
- marry and found a family, e.g. prohibiting mandatory premarital testing, and coerced abortions or sterilizations.

## Exceptions

States may impose limitations on the exercise of some human rights under international law in circumscribed situations. Absolute rights, such as freedom from torture and slavery, can never be abrogated under international law. Public health is sometimes cited as a justification for limiting the realization of the human rights of individuals or groups – e.g. when liberty is restricted by isolation or quarantine laws, and when privacy is violated by notifying an individual’s HIV status to health authorities without his or her consent. However, public health is only a legitimate ground of exception to the exercise of some of these rights in very limited circumstances, and should not be used as a pretext to authorize punitive measures. Public health and human rights are usually complementary, rather than conflicting.

Other grounds of restriction set out in international human rights treaties are: the rights and freedoms of others; morality; public order; the general welfare in a democratic society; and national security. Restrictions based on the protection of public health and these other grounds are only legitimate<sup>30</sup> where they are:

- prescribed by law (i.e. not arbitrary). Specific legislation should be accessi-

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ble, clear and precise so that individuals can regulate their conduct accordingly; and

- are necessary in a democratic society (i.e. the product of the legislature with community consensus) to protect a compelling social need, and proportional to that need (i.e. the least intrusive and restrictive measure that will actually achieve that interest, such as health). There needs to be a balance between the benefits to be expected from the measure and their adverse consequences for the persons concerned, as well as the public interest in the free exercise of the right that is being restricted<sup>31</sup>.

The areas of potential law reform identified in the International Guidelines are discussed below. The discussion is framed in terms of these human rights standards as they apply to HIV/AIDS issues. Consideration is given as to whether there are any possible cases for legitimate restrictions being placed on human rights. They are meant to guide legislators when considering law reform proposals or policies that affect people living with HIV/AIDS.

States Parties to the above-mentioned human rights treaties have a duty to review, and if necessary, repeal and amend their laws, policies and practices which are in breach of obligations, and take the necessary steps to adopt legislative or other measures to ensure respect of, and give effect to, the rights under them.

# III. ANNOTATED INTERNATIONAL GUIDELINES

This substantive part of the Handbook analyses the content of the 12 International Guidelines developed by the Second International Consultation on HIV/AIDS and Human Rights in September 1996. The Guidelines are framed in three broad and inter-connected approaches:

- (A) improving governmental responses in terms of multisectoral responsibility and accountability of processes;
- (B) widespread law reform and legal support services focusing on antidiscrimination, public health protection, privacy, criminal law, and improving the status of women, children, and marginalized groups; and
- (C) support for increased private sector and community participation in the response, including building civil society's capacity and responsibility to respond to HIV/AIDS ethically and effectively.

All three areas are equally important, however, because this Handbook is directed to legislators, it focuses more on the first two areas. This Handbook aims to give an added policy dimension to the Guidelines with detailed context, interpretation and discussion (especially in the area of law reform) of why implementation is necessary. It also sets out practical case studies from around the world to show how success has been achieved in a variety of national environments. The areas identified in the 1998 IPU Windhoek Resolution on HIV/AIDS are of particular interest to parliamentarians and therefore have been highlighted.

## (A) Institutional Responsibilities and Processes

### Guideline 1: National framework

States should establish an effective national framework for their response to HIV/AIDS which ensures a coordinated, participatory, transparent and accountable approach, integrating HIV/AIDS policy and programme responsibilities, across all branches of Government.

For there to be an effective national framework, HIV/AIDS policies and programmes need to be integrated across the executive, legislative and judicial branches of government. Only such an approach can clarify respective roles and ensure that human rights are adequately considered across portfolio responsibilities – otherwise specific issues may be passed over or seen as within others’ mandates. Mechanisms to foster coordination, participation and accountability are set out below with some case examples of national initiatives. A practical consideration in ensuring their effective operation has been to allocate to such committees or bodies dedicated “ring-fenced” budgets, in order to protect against being overtaken by other competing financial priorities. Complementary activities at local level are equally important as responsibility for the actual work of implementation usually rests at the community level. National committees and advisory bodies should be replicated at this local level where possible, as state/provincial governments have important legislative and budgetary decision-making powers impacting on the epidemic.

#### **Interministerial committees**

Interministerial committees can ensure integrated development and high level coordination of individual ministerial national action plans, and monitor and implement further HIV/AIDS strategies<sup>32</sup>. Best practice models of this structure exist in many countries:

- the Thai National AIDS Prevention and Control Committee has been chaired by the Prime Minister since 1991<sup>33</sup>. The Thai NGO Coalition on AIDS is a member of the Committee;
- the South African Cabinet established a 10-member special interministerial committee under the Deputy President dealing with HIV/AIDS in the portfolios of: education; health; welfare and population; home affairs; correctional

services; defence; culture, science and technology; agriculture and land affairs; and transport<sup>34</sup>;

- the French interministerial committee was formed in 1994 to coordinate the national response to AIDS;
- the British Special AIDS Cabinet committee with a large budget was created in 1986 when AIDS became the focus of a high-profile political campaign<sup>35</sup>; and
- the Malawi Cabinet Sub-Committee on HIV/AIDS is chaired by the Vice-President.

Similar committees also exist in India and Botswana. The existence of such committees should not preclude HIV/AIDS issues being considered by existing mainstream, standing ministerial forums, such as in the above-mentioned portfolios. There are also positive reasons for linking consideration of HIV/AIDS issues with other infectious diseases, such as hepatitis B and C, where appropriate. These include not isolating HIV/AIDS as a preferred or special case for government intervention, and resource savings by mainstreaming.

It is preferable that such committees consist of relevant cabinet ministers, but in some countries members are bureaucrats from appropriate portfolios who can also be effective at lower and less political levels of decision-making. It is important that all relevant ministries are included. In Zambia the following cross-portfolio activities have occurred in non-AIDS specific areas:

- the Ministry of Defence has created an orphans' fund for the upkeep and education of former service people;
- the Ministry of Agriculture, Food and Fisheries is training extension workers in social mobilization techniques for HIV/AIDS prevention and care in rural areas;
- the Ministry of Local Government and Housing is establishing AIDS offices in all its units; and
- the Ministry of Tourism is incorporating HIV/AIDS into the curricula of training and education bodies<sup>36</sup>.

## Parliamentary committees on HIV/AIDS

Special parliamentary or legislative committees on HIV/AIDS can provide an ongoing forum for parliamentarians to deepen their understanding of the epidemic through regular briefings and policy discussion, and can serve as a vehicle for law reform. The 1998 IPU Resolution on AIDS recommends the formation of these committees. By including both minor and major party representation in such committees, nonpartisan support of HIV/AIDS policies, programmes and laws can be promoted. Successful examples of



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such parliamentary liaison groups can be found in several countries, including Britain<sup>37</sup>, and Australia<sup>38</sup>. In the UK, the All-Party Parliamentary Group on AIDS (APPGA) was established in 1986 and currently has about 170 members. It exists to “prevent AIDS being forgotten under the weight of all the other distractions that come up every day” in Parliament<sup>39</sup>. The APPGA has identified its aims and objectives as:

- raising awareness of HIV/AIDS issues in Parliament and encouraging balanced policies based on accurate information;
- acting as a bridge between Parliament, the statutory and voluntary sectors, providing a forum for the exchange of information;
- ensuring that HIV/AIDS is kept on the political agenda through parliamentary debates and questions, and meetings with Ministers;
- liaising with other agencies to identify and draw attention to gaps in provision; and
- monitoring legislation to ensure that HIV/AIDS issues are given due consideration, e.g. the Carers’ Bill, Disabled Persons’ Bill, Disability Discrimination Bill, Housing Bill, Offences Against the Person Bill and Pensions Bill.<sup>40</sup>

The APPGA operates through a number of activities including:

- holding meetings at which prominent scientific and other experts brief Parliamentarians around topics such as sex education, overseas development, and treatments;
- collaborating with other All-Party Parliamentary Groups, e.g. those on Penal Affairs, Homelessness, Mental Health, Disability, and Drug Misuse;
- participating in Parliamentary hearings, e.g. responding to the changing needs of people living with HIV/AIDS (PLWHAs) and designing national strategies to meet those needs;
- preparing Parliamentary briefing papers, and background briefings for debates, and assisting in the drafting of Parliamentary Questions, such as on HIV testing needle and syringe exchanges, prevention and prisons;
- holding seminars on working effectively in Parliament, including procedures, influencing legislation and policy, and approaching or lobbying members of Parliament;
- arranging visits to AIDS service organizations to ensure that members are kept aware of frontline activities; and

- providing information and advice to members on all aspects of HIV/AIDS from medical, social and economic perspectives.<sup>41</sup>

## Multisectoral advisory bodies

Multisectoral advisory bodies with professional and community representation, both general and specialist, on legal and ethical issues can address the issues of review and reform. In the area of law reform these advisory bodies can be governmental (such as the Australian Legal Working Party of the Intergovernmental Committee of AIDS)<sup>42</sup>, or nongovernmental (such as the Project on Legal and Ethical Issues Raised by HIV/AIDS of the Canadian HIV/AIDS Legal Network and Canadian AIDS Society, and the AIDS Law Project in South Africa)<sup>43</sup>. The Malaysian AIDS Council, an umbrella organization of 27 groups, has a legal and ethical subcommittee which formulated an AIDS Charter: Shared Rights, Shared Responsibilities in 1995. The Kyrgyzstan Multisectoral Co-ordination Committee on HIV/AIDS/STDs Prevention established a Technical Advisory Group on Policy and Legislation which held consultations in 1996, leading to the revision of the National AIDS Law by Parliament in March 1997.

Other general multisectoral advisory or reporting bodies appointed by governments include:

- the US Presidential Commission on the HIV Epidemic which reported in 1988;
- the British Parliamentary Select Committee for the Social Services which reported in 1989;
- the Canadian Ad Hoc Parliamentary Committee on AIDS which released its report in 1990;
- the German AIDS Enquete Commission of the Federal Parliament;
- the Kenyan Parliamentary Sessional Paper on AIDS which began with the development of national policies in 1994 and was published in 1996;
- the Malawi National AIDS Committee which is an interdisciplinary body chaired by the Minister of Justice; and
- the Philippines National AIDS Council which is required by legislation to include 26 members, including several Parliamentarians, representatives from six NGOs and one PLWHA, two medical organizations, and the heads of the following Departments or agencies: health; education; employment; social welfare; interior and local government; justice; economic development; tourism; budget management; foreign affairs; and information.

#### **Local level activities: decentralization case study**

A successful example of decentralization occurred in the Northern Thailand HIV/AIDS programme in the mid-1990s<sup>44</sup>. The epidemic severely affected Northern Thailand with nearly half of the national HIV/AIDS cases concentrated there, partly due to high levels of injecting drug use and a large commercial sex industry. The initiative was to share authority for policy and programme development, planning, budgeting, decision-making and consultation with provincial level bodies by:

- establishing the Upper Northern HIV/AIDS Prevention Committee to coordinate implementation in six provinces;
- providing block grants directly to the upper North region<sup>45</sup> to facilitate faster, more appropriate and flexible use of the budget for the planned programme, rather than centralized decision-making within a highly politicized and competitive budget allocation process;
- providing an NGO fund with prescreening committees set up in the region, so that decisions could be made by persons in close contact with the local situation and NGOs applying for funds; and
- promoting and supporting roles of NGOs and community-based organizations in prevention and care interventions, demonstrating the effectiveness of the partnership approach in decreasing the spread of the epidemic.<sup>46</sup>

#### **Guideline 2: Supporting community partnership**

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

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#### **Partnership approach**

There is a critical need for governments to actively involve and engage communities at risk and affected by the epidemic. These communities have a unique position of trust, and direct knowledge and experience of how and why infection occurred.<sup>47</sup> Community-based organizations are better placed than government agencies to reach deep into vulnerable constituencies. Structural means need to be created to enable

community consultation in all phases of HIV/AIDS policy design, programme implementation and evaluation. This could occur by including community representatives on the above-mentioned ministerial, parliamentary and advisory forums, preferably by formal attendance but also by inviting written submissions.

Human rights protection should be a central feature of this engagement, as fear of discrimination and public disclosure of HIV status act as significant impediments to community mobilization and advocacy. Adequate funding for community organizations and capacity building is essential to support true partnership, in order to have the benefit of their knowledge and experience working with people directly affected by HIV/AIDS. The most effective responses to the epidemic grow out of people's action within their own community and national context.<sup>48</sup>

## Case studies

Numerous community groups have been established in many countries working with persons living with HIV/AIDS (PLWHAs) in different ways, such as running telephone hotlines, drop-in centres, safe houses and “buddy support”.<sup>49</sup> Government support, especially if accompanied by funding, is important to the sustained success of such organizations. In Uganda The AIDS Support Organization (TASO) was established as a small self-help group in 1987 and has now grown to having 150 staff and almost 2,000 volunteers.<sup>50</sup> Thailand also has some very successful grassroots support organizations, such as the Wednesday Friends' Club run by the Red Cross, the Duang Prateep Foundation in Bangkok and the New Life Friends in Chiang Mai. In Northern Thailand a District Model has been used in villages by CARE. It provides comprehensive community care and focuses on strengthening community partnership and ownership with integrated programming, including the development of clear antidiscrimination policies in training.<sup>51</sup>

The UNDP commissioned a case study on government and civil society interface in the Philippines at the levels of HIV/AIDS national policy formulation and local implementation.<sup>52</sup> The Philippine National AIDS Council was formed in 1992 as a multisectoral body to advise the President on policy development and coordinate implementation of a National Strategy. It has 13 government and 7 NGO representatives, including the President of the PLWHA organization. The Council formulated a National AIDS Prevention Strategy, using a national consultative process, which was respectful of human rights. A key achievement of the Strategy is the mainstreaming of AIDS information and education in government departments responsible for education and the interior. The Olongapo City AIDS Foundation established in 1992 at local level has a successful community-based approach in its massive information campaigns, and care and support programmes. The Inter-Agency HIV/AIDS Network was formed in 1995 in the province of Palawan where there have been no reported case of HIV/AIDS. The Network consists of five governmental, four private and five

nongovernmental organizations and uses prevention information and education campaigns, mobilizes an appropriate community response, links multisectoral expertise, and integrates HIV/AIDS into members' programmes.<sup>53</sup>

On the other hand, a 1997 UNDP study of involvement of PLWHAs in policy and programme development<sup>54</sup> in Asia found a general inability to comprehend, lack of serious consideration and disinterest on the part of senior bureaucrats and medical professionals regarding the benefit of PLWHAs' involvement. In many countries there was no involvement of PLWHAs beyond being mere patients and recipients of services. In other countries such as Thailand, the development of a local PLWHA movement was facilitated by the government's willingness to work as partners with PLWHAs by providing political leadership, allocating funds and making appointments to decision-making bodies in a supportive and enabling environment (see Part C below).

## **(B) Law Review, Reform and Support Services**

The following areas of the law have been identified, based on worldwide experience and case studies, as the mostly likely ones where human rights issues will arise which impact on the epidemic. Legislative checklists requiring affirmative or negative responses are included to assist with implementation of this technical area. The 10 checklists in the text identify areas requiring legislative reform in all five of the Guidelines covered in Part (B), and the allied Guideline 10 (Codes of Practice), which is in Part (C) Promotion of a Supportive and Enabling Environment. The actual process of law reform which promotes respect for human rights in several countries is described below.

### **Guideline 3: Public health legislation**

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

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## National examples of reform

### *Nicaragua*

In Nicaragua a Bill on human rights and AIDS was drafted by two NGOs, Fundación Nimehuatzin and the Center for Constitutional Rights. Workshops on various drafts were run in 1996 by the Network on Ethics, Human Rights and Judicial Aspects of HIV, consisting of representatives from these two NGOs and other human rights NGOs, members of Parliament, the affected PLWHA community, a prevention group from the gay community, the United Nations Development Programme, the Pan American Health Organization and the National AIDS Programme. The Network provided expertise to parliamentarians, as well as sensitizing various community organizations and the general public to human rights issues. A communications strategy was also used, involving the production of a video illustrating the ethical and human rights aspects of the law and HIV/AIDS using a dramatic story telling format. Major television channels, as well as public service announcements showed the video on television, radio and billboards. Since the law was enacted<sup>55</sup>, the video has been used for training purposes. The Network now has a technical team working on elaborating regulations under the law, which covers issues such as antidiscrimination, confidentiality and autonomy of the person.<sup>56</sup> The special session of the Nicaraguan Parliament on this issue described above was a major impetus and support for the legislation.

### *Mexico*

In Mexico a law for the Prevention and Control of Infection by HIV came into effect on 17 January 1995. Its genesis was in the unprecedented cooperation between 17 governmental bodies and 19 NGOs.<sup>57</sup> The law is enshrined in the Constitution and takes precedence over provincial or State law. It addresses issues such as confidentiality and prohibits mandatory testing and discrimination in specified areas of activities or services – marriage, employment, education, medical treatment, accommodation, immigration or emigration.

### *Argentina*

In Argentina a national law on AIDS which promoted respect for human rights was passed in 1990, following the enactment of many coercive laws at the provincial level. The law covers issues of discrimination, confidentiality (subject to exceptions, such as treatment and care purposes, criminal, family law, or adoption cases) and informed consent to testing (subject to exceptions, such as blood donation and immigration).<sup>58</sup>

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#### *Philippines*

The Philippines National AIDS Council (PNAC) includes representation from both Houses of Parliament (the Chairpersons of the respective Committees on Health), as well as the Presidents of the Leagues of Governors and City Mayors. The Philippines Senate created the Ad Hoc Committee on AIDS which drafted the *AIDS Prevention and Control Act 1998* and the Senate Committee on Health ensured its enactment. Features of the comprehensive Act which gives the National AIDS Council a legislative basis, include:

- requiring written informed consent and prohibiting compulsory HIV testing (such as for employment, travel, medical services, and admission to educational institutions), unless authorized by the Act (e.g. blood or organ donation);
- guaranteeing the right to confidentiality, subject to certain exceptions, e.g. court proceedings (but with a requirement that medical records be sealed, only to be opened by the judge);
- prohibiting discrimination on the basis of actual, perceived or suspected HIV status in the areas of employment, schools, travel, public service, credit and insurance, health care, and burial services;
- establishing universal infection control guidelines for surgical, dental, embalming, tattooing and similar procedures;
- prohibiting misleading advertising of drugs and other products for HIV/AIDS prevention, treatment or cure;
- requiring educational authorities to integrate HIV/AIDS prevention education at intermediate, secondary and tertiary levels (although limits are placed on the use of explicit materials and promotion of birth control);
- mandating HIV/AIDS information as a health service, and requiring specific programmes in the workplace, by local governments, and for overseas travellers, tourists and other communities; and
- recognizing the role and utilizing the experience of affected individuals in information and education campaigns, as well as providing access to health care, community-based services and self-help programmes.

#### *Canada*

Law reform has been approached comprehensively by the Canadian HIV/AIDS Legal Network and the Canadian AIDS Society. These NGOs began a joint Project on Legal and Ethical Issues Raised by HIV/AIDS in 1995 and have held many workshops to gauge community responses. The Project has issued a literature

review, a regular newsletter, discussion papers and reports on various topics including: prisons; discrimination; criminal law; testing and confidentiality; gay and lesbian legal issues; and aboriginal communities (discrimination, testing and confidentiality). These high quality documents have been used for resource and advocacy purposes, as well as consensus building in promoting law reform.

### *Australia*

A process of law reform similar to that which took place in Canada occurred in Australia, but was driven by government rather than by NGOs. The Legal Working Party (LWP) of the Intergovernmental Committee on AIDS issued nine discussion papers during 1990-92 on the topics of: public health; injecting drug use; homosexuality; sex work; employment law; civil liability; media law; and therapeutic goods legislation. The LWP was established under the First National HIV/AIDS Strategy and was the first dual portfolio law reform body (health and attorney-general's) across all jurisdictions, i.e. Federal, as well as State and Territory Governments. It issued a Final Report following public submissions on preferred options presented in the discussion papers in 1992, of which approximately half have been implemented.<sup>59</sup> Both of these case studies in Canada and Australia use the English law reform commission model of comprehensive research and community consultation to reach balanced recommendations. It is debatable whether the location of law reform bodies within NGOs or governments influences the effective implementation of reports.

### *United States of America*

Although there have not been similar national law reform projects in the USA, there have been projects which monitor legal developments in the HIV/AIDS area – the AIDS Litigation Project funded by the Department of Health and Human Services has surveyed the results of nearly 600 court and human rights commission cases during 1991-1997<sup>60</sup>, and the Intergovernmental Health Policy Project of the George Washington University annually summarizes AIDS laws from legislative sessions in 50 States.

### *India*

Positive results can also come from efforts opposing legislation, as occurred with the blockage of the *Indian AIDS Prevention Bill* in 1989, which had coercive provisions similar to those in the 1898 *Lepers Act*.<sup>61</sup>

Public health has been recognized at least since the nineteenth century as a government function. Beyond the management of communicable diseases, public health is concerned with access to medical services, the physical, biological and social environment



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(e.g. regulation of pollution, food standards, drug safety, water hygiene and sewerage)<sup>62</sup>. The public health and sanitation movements, which emphasized society's obligation to ensure conditions under which people can be healthy, promoted collective rather than individual responsibility for health. Under utilitarian principles positive interventions (e.g. treatment) were taken to protect the welfare of citizens, and preventive actions (e.g. vaccinations) were required so that others would not be harmed. Scientific knowledge formed the basis of measures to curb epidemics, such as plague, leprosy, cholera, polio, smallpox, or venereal disease and tuberculosis. Unfortunately, throughout most history there has been a stigmatized association between epidemic diseases and marginalized groups – the poor, immigrants, particular ethnic or social groups have all been scapegoated at various times and in various locations.<sup>63</sup>

Antiquated legislation initially formulated in the last century to address diseases such as leprosy and cholera has now been inappropriately extended to HIV/AIDS. This is not appropriate since HIV/AIDS is not casually transmitted. An example of casual transmission is droplet infection, which occurs with sneezing, coughing or sharing utensils (e.g. drinking cups or cutlery). Laws prohibiting people with HIV from working in certain industries (such as food-handling), or using public transport<sup>64</sup> are neither necessary nor effective in addressing the epidemic. On the other hand, principles and strategies formulated in the International Guidelines for HIV/AIDS and Human Rights can be linked to the control of other communicable diseases, such as sexually transmitted diseases, where it is appropriate. There can be benefits in mainstreaming, rather than having HIV/AIDS treated as an exceptional case, in relevant areas of both the law and administrative implementation.

Government has both the capacity and responsibility to provide leadership in producing an appropriate public health legislative response to the epidemic in order to fulfil the individual's right to health. It is appropriate that public health legislation explicitly funds and empowers authorities to provide the following comprehensive range of prevention and treatment services:

- information and education, for the general public and targeted populations;
- voluntary testing and counselling;
- STD and sexual reproductive health services for all;
- condoms and other means of prevention, such as bleach and clean injecting equipment;
- drug treatment;
- care and treatment for AIDS-related illnesses, including pain prophylaxis; and
- epidemiological surveillance.

## Voluntary testing and informed consent

Laws should require specific informed consent before HIV testing is done; otherwise a person's liberty and privacy are at risk of being violated. The potential economic and social consequences of a positive diagnosis on individuals, including possible discrimination, make it essential that their decision to be tested is made with full prior knowledge. The availability of treatment drugs in industrialized countries provides a strong incentive to seek HIV testing for individuals who know that they are at risk of infection so that they are able to access medication at an earlier stage of infection. Pre- and post-test counselling is essential not only for psychosocial reasons, but to maximize prevention and care messages and services. Legislation in several countries requires that test results should be given in person (rather than by telephone) to the individual who has been tested, and privately to ensure confidentiality and adequate support. Some adaptation will need to be made for local cultural and social conditions – for example in the Netherlands there is an enforceable legal right not to be informed of a test result.<sup>65</sup>

In many countries anonymous test sites are available so that a person does not need to disclose his or her identity. This privacy protection has been subverted in some countries by legislation which is contingent on the test result being negative<sup>66</sup>. Where home test kits are legally available, governments should ensure quality control under therapeutic goods legislation, while also providing counselling and referral services for clients using them. Mechanisms to prevent misuse of the tests, such as by employers or insurers, should be covered under antidiscrimination legislation.

Lingering paternalism of the medical profession in some countries has enabled widespread mandatory testing under the guise of general consent to medical services. The European Court of Justice has held that subjecting candidate employees to a disguised HIV test without informed consent is illegal: *X v. Commission*.

Practical remedies for unauthorized HIV testing, such as covert testing of blood or other body fluids (e.g. urine), should be provided under legislation. Some countries require medical professionals to use consent forms (included as a schedule to subordinate legislation such as public health regulations) as part of the request to the laboratory performing the test, in order to provide proof of specific informed consent. These forms can protect doctors against legal proceedings, but they should be structured in such a way that privacy of the person being tested is preserved. A two-part form is sometimes used – one part has the signed name of the person consenting and is maintained in the doctor's records, and the second part is sent to the laboratory with information de-identified by the use of alphanumeric codes (e.g. the date of birth, sex and/or the initials of a person's name).

Public health legislation can positively influence medical practices, but legislation should also provide enforcement mechanisms for individuals to obtain redress.

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Examples of successful mechanisms include medical ombudspersons and health complaints authorities established under the law. These tend to be more accessible, simple, quick and cheap than courts. This should not preclude health authorities from pursuing legal proceedings under public health legislation, or disciplinary proceedings to professional registration boards. Similarly, individuals should have the option to seek redress under civil liability law.

Obligatory testing<sup>67</sup>, i.e. testing without informed consent, has been targeted at groups in some countries including:

- migrants, refugees or travellers;
- military personnel;
- pregnant women;
- children who are being adopted, or subject to custody/access orders;
- couples intending to marry;
- people seeking insurance/superannuation, or accommodation;
- participants in certain sports, such as boxing;
- hospital patients, e.g. before surgery or where needle-stick injuries have been suffered by health-care workers;
- inmates of institutions such as prisons and facilities for the mentally ill, developmentally disabled, or people with severe physical disabilities;
- employees, with sometimes a particular emphasis on certain occupations such as health-care workers, pilots, entertainers, truck drivers, fishermen; and
- people subjected to the criminal law, such as sex workers, injecting drug users and men who have sex with men.

Testing of these groups is in violation of the nondiscrimination principle under international human rights law. The only clear exception would be in the case of blood, and human tissue/organ donation where there is an obvious public health imperative to perform HIV testing, and a legal duty of care towards potential recipients who need to give fully informed consent to the donation. Lack of involuntary testing does not imply that voluntary testing should not be actively encouraged. In fact the converse is true – there are very good reasons for promoting voluntary testing in certain groups, such as pregnant women, both for the mother’s and child’s health (e.g. optimal access to antiretroviral treatments).

There are also strong public policy grounds for not using involuntary testing:

- cost and ineffectiveness, as it diverts scarce resources from prevention and care programmes;
- the information obtained may be unreliable unless the test is repeated at a later stage, as the person being tested may be in the “window period” (not yet producing antibodies) and therefore have a negative result;
- counter-productivity in making people hide their behaviour that may have put them at risk of HIV infection, thereby making contact with prevention and care programmes much more difficult;
- it is easily bypassed in certain scenarios, such as marriage licences where the couple may marry in another jurisdiction or simply choose to live in a de facto relationship, or in other cases where false “AIDS-free certificates” are obtained, e.g. for sex work, or travel;
- use for discriminatory purposes, such as refusal of employment, segregation of HIV-positive prisoners, or denial of migration applicants. This ignores the long asymptomatic period during which productive work can be performed (and taxes can be paid). It is also inappropriate given the lack of screening for diseases causing an equal or greater burden on the health care system;
- it undermines individual responsibility to avoid infection, as people can rely on the assumption that others are HIV-negative;
- it weakens compliance with universal infection precautions by falsely reassuring people that they would have prior knowledge of others’ HIV status, thereby leading to less careful practices; and
- it sends a wrong message to the community that HIV/AIDS is a problem of “risk groups”, thereby promoting an “us and them” mentality and creating further fear, denial and stigma.

The use of blood samples given for other purposes in unlinked HIV testing of certain groups (e.g. newborns) can raise ethical concerns which need to be resolved at a national level. A balance needs to be weighed between the individual’s right to privacy in respect of the blood given by them for another purpose, and the community value in having data on the course of the epidemic which would not be available otherwise.

In Uganda HIV infection prevalence was monitored using sentinel surveillance, which indicated that the rate is falling for pregnant women in urban areas (the data were also supported by surveys of changes in sexual behaviour).<sup>68</sup> “Sentinel surveillance is the performance of HIV antibody tests on blood specimens drawn and collected for another legitimate purpose in selected populations, such as clients of STD clinics, injecting drug users and pregnant women, that will provide an indication of HIV trends associated with specific risk behaviour or practices in each category. Personal identifiers are removed and results cannot be linked to the individual whose blood is being tested.” On the other hand, in the Netherlands there is an enforceable right of bodily integrity under the Civil Code to object to research on one’s bodily substances, which means that individuals can prevent sentinel testing of their blood if they wish.<sup>69</sup>

## Notification of coded information

There is a public health need to collect data for several reasons – to enable:

- action in individual cases to prevent further infections by interrupting the chain of transmission, e.g. triggering contact tracing;
- surveillance of infectious disease trends in relation to tracking the course of the epidemic, such as risk factors;
- monitoring of incidence and prevalence in order to plan and evaluate prevention programmes;
- cost effective application of resources for controlling the epidemic by ensuring effective planning which takes into account accurate epidemiological data.

Apart from the first situation (which will be considered in the next section below), coded data would serve all the above-mentioned purposes. Diagnosis of HIV infection is usually performed by laboratories, whereas AIDS is a clinical diagnosis made by doctors, nurses, or other qualified health-care providers. Requiring notification of coded data on *confirmed* HIV cases to authorities under public health legislation protects human rights because it supports the rights to health, life and information. Some countries (e.g. Norway) require laboratories to send a form that is attached as a schedule to public health regulations. This requirement has the advantage of making the data set uniform and more easily used for epidemiological purposes (and deterring unauthorized purposes because irrelevant information, such as personal markers, is not collected). Strict controls on data protection are still necessary to allay concerns that codes may somehow be broken. The use of identifiable data, on the other hand, raises privacy concerns which will be considered.

## Partner notification

The issue of whether people living with HIV/AIDS should be subjected to coercive public health strategies, particularly partner notification, has been debated in most legal systems. In many communities there is a history of medical professionals having an ethical and sometimes legal obligation to protect others from infection by tracing contacts of those infected by serious diseases, particularly where they would not otherwise be aware of their infection.

On the other hand, patient confidentiality is a central part of the doctor-patient relationship under the law, and is the basis upon which sensitive information relevant to health status is voluntarily given. The issue of patient confidentiality also applies to other health-care professionals, such as nurses, welfare workers and counsellors, with confidentiality obligations. It is recognized that coercive strategies are inappropriate, ineffective and counter-productive because they deter those at risk of infection from presenting early for counselling, testing, treatment and support. Coercive models of notification used in the area of sexually transmitted diseases (STDs) or tuberculosis (TB) are inappropriate for many reasons, including the fact that there is no cure for HIV. Comprehensive contact tracing in the case of HIV would be practically impossible without extensive and expensive surveillance techniques, which would place unacceptable limits on civil liberties.

The International Guidelines on HIV/AIDS and Human Rights support voluntary partner notification, but with provision for exceptional cases. They recommend that public health legislation should authorize, but not require, health-care professionals to notify sexual partners of their patient's HIV status in carefully defined situations. In some jurisdictions the partner notification protocol codified under public health legislation requires peer consultation, either the seeking of advice from another professional or an expert panel specifically established by health authorities to provide ethical guidance on partner notification cases. The discretion granted to health-care professionals would also protect against breach of confidence actions by their clients, and from civil liability for failure to notify a partner.

## Detention or isolation/quarantine

There is no public health justification for imposing civil detention solely on the basis of HIV status, rather than individual behaviour. Several jurisdictions require establishments (such as bath-houses) perceived to be conducive to the propagation of HIV to be closed by authorities, despite the opportunity to use them as sites for safer sex education. In some countries quarantine or detention provisions applicable to casually transmitted and usually curable disease are inappropriately extended to include HIV. The liberty of people living with HIV should be restricted only in exceptional cases of illegal behaviour, and due process protections should be guaranteed.

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Powers in public health legislation to place restrictions on the residential circumstances and employment of HIV-positive people who put others at unreasonable risk of infection should be graded according to the exceptional circumstances of the case. Isolation should only be used as a last resort and for limited, rather than indeterminate, periods of time. It is preferable for such measures to be court-ordered, or at least court-authorized within a short period of time (e.g. three working days, after which time they lapse unless validated by a court), rather than being simply a power exercised by health authorities. Graded interventions are recommended. For example, in the first instance, a written warning should be issued from health authorities outlining reasons why the person should cease behaving irresponsibly, and warning that if they do not do so, formal proceedings will be instituted. The criteria for the exercise of coercive powers should be structured as objectively as possible – that the person:

- has in the past willfully or knowingly behaved in such ways as to expose others to a significant risk of infection;
- is likely to continue such behaviour in the future;
- has been counselled without success in achieving appropriate and responsible behavioural change; and
- presents a danger to others.

The type of graded interventions which could be applied at later stages when this warning has been breached include: directions to take precautions, such as safer sex; warnings to refrain from certain activities, such as sharing drug injecting equipment; residence at a specified place, e.g. supported accommodation run by an NGO; supervision by health authorities or medical practitioners; regular medical examinations, such as testing for STDs to ensure that unprotected sex has not occurred; abstention from specified work, such as unsafe sex work. Due process protections which are important include:

- adequate notice of proceedings;
- urgent rights of review/appeal to a higher tribunal or court;
- right to legal representation;
- notification of rights, explaining the nature of relevant orders and obligations and rights of review/appeal.

Some countries ensure under legislation that legal rights include interpreters, legal aid and free or low-cost review and appeal. Proceedings under public health legislation should ordinarily be held *in camera* (in private, as opposed to public), because of the great stigma associated with HIV/AIDS, and the social and economic consequences which may flow from unauthorized publication of an individual's HIV status. A pre-

sumption of private proceedings could be rebutted where the interests of the individual and justice would be best served by an open hearing, e.g. when a public figure wishes to publicize his or her own case. Most legal proceedings (exceptions may exist for minors, mental health and matrimonial cases) are held in public in order that justice is seen to be done, as well as actually done. This important safeguard against abuse of power may be maintained by lesser privacy protections, such as non-publication orders, e.g. the identity of the parties is protected by the use of pseudonyms in published reports of proceedings.

## Blood safety

Both the International Guidelines and the IPU 1998 Resolution recognize that public health legislation should ensure that the blood/tissue/organ supply is free of HIV and other blood-borne pathogens in order to fully protect the right to health.<sup>70</sup> The risk of infection by the transfusion of contaminated blood is over 90%. According to UNAIDS, up to 4 million blood donations a year worldwide are not tested for HIV or other infections.<sup>71</sup> This can be avoided by proper screening of blood, and by requiring donors to declare that they have not engaged in behaviour that would place them at risk of infection. This declaration can be made by use of a questionnaire. It is important that the questions relate to actual behaviour, rather than membership in a particular group. Informed consent by the recipient of the donation is important for many individual human rights reasons, but also the community need to prevent unnecessary usage of a scarce resource.

Many countries have blood shield legislation which protects hospitals, blood banks, tissue/organ suppliers, health-care professionals, employees and donors from liability where codified procedures have been complied with, i.e. screening of the blood, and donor declarations signed within a prescribed period, such as 12 hours before donation. Compensation would only be available where there is evidence of negligence, willful misconduct or false declarations. It is important that jurisdictions have complementary legislation, so that coverage is uniform where there is intra- and inter-country movement of blood, blood products (usually to treat haemophilia), semen, cell/organ supplies for transfusion or transplantation. Policy reasons for limiting liability are: the blood supply is essential to save lives; although screening is usually reliable, it cannot detect infection where a person is in the “window period”; blood often cannot be substituted with safer synthetic substances (e.g. plasma expanders); in many countries blood is donated.

Although many countries have legislation regulating blood donations, screening and transfusions, it is often not adequately enforced. UNAIDS identifies the three vital elements for safe blood supplies as:

- a national non-profit blood transfusion service which is accountable to the government, and developed within the framework of the national health service, such as in Namibia, South Africa, Zambia and Zimbabwe;



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- voluntary (non-remunerated), as opposed to paid or professional, donors with a low risk of infection are used;
- donated blood is screened for HIV and other diseases (hepatitis B/C and syphilis).<sup>72</sup>

The reasons for excluding paid donors is that often they come from the most vulnerable sectors of society, have poor health and may be at risk of various infections from behaviour such as sharing needles and syringes where the main purpose of selling blood is to buy drugs. Voluntary donors, on the other hand, donate at properly-spaced intervals, without risking their health. The reasons for inadequate screening in some countries are often financial and/or logistical – screening only occurs in major cities and not rural areas; storage problems (e.g. no electricity for refrigeration); lack of trained staff; and poor organization in distribution and storage of reagents and other materials used in testing blood. Political commitment is essential to change this situation through the provision of adequate budgets, management resources and regular independent monitoring of institutions providing the service.

A 1993 study of the Ugandan Blood Transfusion Service showed the cost-effectiveness of government subsidization of proper HIV screening, by averting 1863 cases of primary, and an estimated 415 secondary, cases of infection in that year.<sup>73</sup> A similar study in Zimbabwe assessed the cost-effectiveness of combining donor deferral and screening of blood<sup>74</sup>. In India the Supreme Court ordered the creation of a National Council for Blood Transfusion, the licensing of blood banks, and eventual end of professional sale of blood following a petition by an NGO against government agencies responsible for blood safety<sup>75</sup>.

#### **Infection control**

Universal infection control precautions should be required in health-care and other settings involving exposure to blood and other bodily fluids. Implementation of this requirement under public health legislation (e.g. as required in some jurisdictions such as Alberta in Canada, California in the USA and New South Wales in Australia) must be backed by resources for appropriate training of staff, as well as the supply of adequate equipment, such as gloves, non-reusable needles and syringes, autoclaves and other cleaning devices. In Argentina laboratories have been closed or placed under judicial control where disposable materials have been reused, following a union complaint when a worker was allegedly infected.<sup>76</sup> In some jurisdictions detailed guidance on these precautions have been developed by health authorities, in consultation with professions and communities, and codified, making them the applicable standard of care in negligence actions. Education campaigns are needed to support such programmes, particularly in countries where injecting medication is popular, but sterilization performed by practitioners, such as traditional healers, is not adequate.<sup>77</sup>

## CHECKLIST – PUBLIC HEALTH LAW

1. Does the legislation empower public health authorities to provide the following comprehensive prevention and treatment services:

- information and education;
- voluntary testing and counselling;
- STD, sexual and reproductive health services;
- means of prevention, i.e. condoms and clean injecting equipment;
- medication, including for pain prophylaxis?

2. Does the legislation require specific informed consent, with pre- and post-test counselling to be obtained from individuals before they are tested for HIV in circumstances where they will be given the results of the test (ie not unlinked, sentinel surveillance)? Does the legislation provide for any exceptions to individual testing with informed consent only with judicial authorization?

3. Does the legislation only authorize the restriction of liberty/detention of persons living with HIV on grounds relating to their behaviour of exposing others to a real risk of transmission (i.e. not casual modes, such as using public transport), as opposed to their mere HIV status?

Does the legislation provide in such cases the following due process protections:

- reasonable notice of case to the individual;
- rights of review/appeal against adverse decisions;
- fixed periods of duration of restrictive orders (i.e. not indefinite);
- right of legal representation?

4. Does the legislation authorize health-care professionals to notify sexual partners of their patients' HIV status in accordance with the following criteria:

- counselling of the HIV-positive patient has failed to achieve appropriate behavioural change;
- the HIV-positive patient has refused to notify or consent to notification of the partner;
- a real risk of HIV transmission to the partner exists;
- the identity of the HIV-positive patient is concealed from the partner where this is possible;
- necessary follow-up support is provided to those involved?

5. Does the legislation provide for protection of the blood, tissue, and organ supply against HIV contamination (i.e. requiring HIV testing of all components) ?

## Guideline 4: Criminal laws and correctional systems

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

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### Transmission/exposure offences

Many countries have specific criminal offences for the intentional exposure or transmission of HIV. The existence of these offences has little impact on the spread of the virus, given that the vast majority of cases of transmissions occur at a time when the infected person is unaware of his or her own infection. Such laws divert attention and resources from measures which do make a difference in curbing the epidemic, and can in fact be counterproductive because of the danger of further stigmatizing alienated groups, already treated as outsiders by society. By placing blame on one party, the criminal law undermines public campaigns aimed at placing responsibility for adopting preventive measures on both parties engaging in risky behaviour.

Coercion is a crude tool in educating for behaviour change, particularly in areas of intimate private activity like sex. Inevitably scapegoating occurs with a focus on unpopular minorities, and people living with HIV are seen in the public mind as potential criminals. The type of cases likely to come to the attention of prosecutors often involve members of vulnerable groups who are of interest to authorities for a variety of reasons (e.g. mental illness), and likely to be inarticulate and/or poor. Variable or targeted law enforcement can be arbitrary, and minorities are often subjected to intrusive policing practices.<sup>78</sup> Potential abuses in enforcement exist for vulnerable populations such as gay men and sex workers because of discriminatory judgments and assumptions about their lifestyles.

Criminal penalties for making false blood-donor declarations do not have the same negative policy implications as private behaviour where transmission may occur. This is because the right to health is clearly violated by the use of contaminated blood and there is no countervailing or legitimate public interest in donating infected blood.

On the other hand, there are not usually offences for perinatal transmission because of the overwhelming countervailing interest in childbirth. The risk of a mother transmitting HIV to a child at birth or through breastfeeding is thought to be somewhere between 13 to 48% and can be greatly reduced by the administration of antiretroviral therapy (e.g. zidovudine). This scientific evidence about the actual risk of transmis-

sion should be seriously considered by states which routinely force HIV-positive women to have sterilizations and abortions in violation of the human right to found a family.

Punishment under the criminal or public health law should be reserved for the most serious culpable behaviour.<sup>79</sup> Relevant charges for HIV exposure/transmission include attempted murder, assault and battery, unlawfully causing bodily harm, or other offences relating to public nuisance, dangerous acts, and noxious things. Society and the individual concerned may not be well served by imprisonment of offenders under such laws for a number of reasons. The risk of HIV transmission is increased in the prison environment as a result of higher risk behaviour without access to preventive information and measures. Imprisonment is less likely than counselling and social support to change behaviour in the community. In addition, adequate health care and other facilities or privileges may not be available for HIV-positive prisoners in some prisons.

It is preferable for such cases to be treated under general criminal, public or mental health law provisions, provided that such application is appropriate. In one country increased sexual abuse of minors by perpetrators wanting to avoid HIV infection prompted legislators to make rape a capital offence in 1990. Not only was this contrary to international human rights obligations, but the law was counterproductive as the number of cases increased.<sup>80</sup>

If a new offence is created then the following issues should be considered:

- the offence should be generic rather than HIV specific and apply to other serious communicable diseases, but with discretion in sentencing based on the curability of the disease, e.g. STDs;
- difficulties with evidentiary issues need to be addressed, such as foreseeability (i.e. that the accused knew that the act he or she was contemplating was criminal), intent (*mens rea*), causality (i.e. that the accused's conduct did in fact infect the victim, as opposed to another source or contact) and consent. Criminal responsibility is usually based on an individual's capacity to make voluntary and intentional choices for acts which he or she understands the significance of;
- the coverage of the legislation should be limited to deliberate or intentional acts. Some countries have offences for reckless, negligent or willfully blind, as well as intentional, behaviour after unsafe activity, to ensure that culpability is not avoided by refusing to be tested for HIV. The general legal test of recklessness is whether the accused foresaw the result of his or her conduct, but nevertheless took the risk of bringing it about. There is a danger that any criminal provisions impacting on testing (seen by some commentators as "backdoor" mandatory testing and punishing mere ignorance<sup>81</sup>) could act as deterrents and undermine public health;

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- the consequences of the criminal behaviour should be specified. In some countries legislation punishes endangerment without actual infection, because of the deterrent nature of such laws and the avoidance of evidentiary problems in proving harm. The main argument in support of such legislation is that when public health measures aimed at changing behaviour fail, then the intervention of the criminal law as a last resort should not have to wait until infection occurs;
- it is important that objective criteria based on scientific evidence are used to measure the actual degree of risk involved in the behaviour concerned. For example, early cases brought against HIV-positive people for spitting are inappropriate as there is no real risk of transmission. A protocol should be developed between health and law enforcement authorities to ensure that only cases with a scientifically established risk of infection are brought before the courts;
- care should be taken in classifying a syringe filled with HIV-infected blood as a “deadly weapon”, to ensure that it does not discourage the return of used equipment to needle and syringe exchanges; and
- the modes of transmission should be specified – usually sexual acts, as other modes of transmission, such as sharing needles and syringes, may not be included because of public policy issues regarding consent to the use of illegal drugs.

Civil law which seeks to deter wrongdoing and compensate those who are injured by it, is sometimes used to provide remedies for aggrieved individuals. Although it has a lower standard of proof than criminal law, there are many practical obstacles to proving fault in civil litigation, such as legal expense and delay, which may not make it worthwhile to pursue an uninsured defendant.

#### *Defences*

Defences should be available to such offences. Many public health offences contain specific defences in the case of informed consent by a partner (this class should not be restricted to de jure or de facto couples, but any couple having sex). In some jurisdictions marriage is a complete defence, with or without consent.<sup>82</sup> Such a provision unfairly discriminates between married and unmarried persons who have sex, and implies that there is no need for safer sex in the case of married couples. This puts married women at a disadvantage in negotiating safer sex generally, and being able to insist on the use of protective measures.

It has been argued that consent should not be available as a defence as infection results in a health and welfare burden on the community. This, however, ignores the signifi-

cant privacy and autonomy interests of individuals being able to choose to engage in sexual activities without state intervention. Draconian measures that prohibit HIV-positive people from having sex, even with informed consent, are impossible to enforce and undermine public health campaigns designed to encourage people to present themselves early for counselling, testing, treatment and support. Use of preventive measures should be a full defence against charges relating to exposure without consent – either inherently, because there would be no intention to expose to infection where, for example, condoms are used, or explicitly. More problematic is the rare case where preventive measures are used but fail, e.g. a condom breaks, and infection occurs. Legal recognition should be given to the use of preventive measures, thus providing further incentive to use them. One possible solution is to create a partial defence to such offences, or to grade the offences in terms of their seriousness.

## Needle and syringe exchanges

Criminal law can impede efforts to reduce the very high risk of HIV transmission among injecting drug users, and the provision of HIV-related treatment and care. A harm-reduction approach accepts that illicit drug use is entrenched in many countries (an estimated 5 million injecting drug users in 120 countries<sup>83</sup>). It regards the lessening of health, social and economic costs as the paramount task, with the reduction of drug supply as only one of the means to achieve this result. Several countries (Nepal, Australia, New Zealand and parts of western Europe, such as Switzerland and the Netherlands) have introduced needle and syringe exchange programmes with legislative authorization, providing immunity against drug-related offences.

An example of an NGO outreach project is the Return Foundation in St Petersburg which ran a touring bus with a needle exchange, advice on drug use and medical assistance.<sup>84</sup> NGOs can have successful links with private sector partners, for example, the Lindesmith Center of the New York Open Society Institute cooperated in the establishment of harm-reduction projects in Ukraine and the Republic of Moldova.<sup>85</sup> Several jurisdictions have also decriminalized or removed legal impediments to the possession, distribution and dispensing of needles and syringes. A politically less controversial alternative has been to promote the use of bleach to clean used injecting equipment. One interpretation of harm-reduction has been the decriminalization of drug use, with trials in Switzerland and the Netherlands of lawful heroin provision to users who did not succeed in previous treatments.<sup>86</sup>

Countries which have a harm-reduction approach tend to have avoided the high incidence of HIV among injecting drug users in some other countries. This approach aims to educate users about the need for safe injecting behaviour, and facilitate safe behaviour by providing easy access to clean injecting equipment. The sensitivity in debate surrounding the introduction of such programmes relates to the continued illegal status of the drugs which are being injected in sterile equipment, and whether criminal

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acts are implicitly condoned or encouraged by the existence of such programmes. Evaluations of such programmes have shown that they have not encouraged greater use of drugs, but in fact have increased demand for drug treatment, decreased the number of unsafely disposed of used equipment, and helped contain the HIV/AIDS epidemic.<sup>87</sup> A study in North America, Europe, Asia and the South Pacific of 29 cities with needle exchange programmes found a decline in incidence of HIV by 5.8%, while 52 cities without needle exchanges had an increase of 5.9%.<sup>88</sup> One successful example is the needle and syringe exchange programme established by an NGO in Nepal in 1992 which has contained HIV prevalence at under 2% while neighbouring countries' prevalence has soared to about 70% among injecting drug users (Yunnan Province in China and Manipur State in India).<sup>89</sup>

For needle and syringe exchanges to operate effectively, the law needs to address the following issues:

- the class of persons to whom they apply must be identified – needle and syringe exchange workers, pharmacists, medical practitioners and possibly even intermediaries who are genuinely facilitating the programme (i.e. volunteer associates or fellow users, rather than suppliers);
- the range of activities should be broad enough to cover the actual exchange of needles and syringes, as well as related educational tasks, such as production and distribution of materials (pamphlets and videos) and relevant equipment (bleach, swabs and sterile water), publicizing the existence of the exchange (e.g. a roster where the service is mobile), and encouraging safer injecting practices;
- providing immunity against minor drugs charges (e.g. possession), where used needles and syringes are disposed of in approved containers, otherwise trace elements of illegal drugs found in them could be used as evidence;
- prohibiting the evidentiary use of information regarding the supply of sterile needles and syringes in drug-related criminal proceedings, which would prevent programme records or workers being subpoenaed by police;
- ensuring appropriate police liaison and training occurs so that health authorities can explain the importance of the programme, and clear management directives are given in support of the programme, so that users are not inhibited by fear of police harassment or surveillance of needle and syringe exchange sites; and
- the use of vending machines which take special tokens to avoid unauthorized use (e.g. by children), promote links with support services where the tokens would be available, and aid anonymity and ease of access, particularly out of business hours.

Other issues needing review are offences for possession of non-injecting (e.g. smoking) equipment which drive users to injecting behaviour. Wider issues such as diversion of minor drug offenders from the prison system, because of the higher risk of unsafe injecting there, and use of non-custodial sentences are important but beyond the scope of this Handbook.

## Sexual acts

Criminal laws prohibiting specific sexual activity between consenting adults in private, such as adultery, sodomy, fornication or acts “against the order of nature” or social order or morality, can impede the provision of HIV/AIDS prevention and care programmes. Many jurisdictions have repealed these laws because they are ineffective and out-of-date, and more recently and urgently, on public health grounds. One example is the Russian Federation where a law criminalizing homosexuality (enacted over seventy years ago) was repealed in 1992. Protection of the human rights of privacy and equality also support repealing this legislation. In *Toonan v Australia*, the Human Rights Committee found that the right to privacy was breached by laws which criminalize private homosexual acts between consenting adults, noting that:

“...the criminalization of homosexual practices cannot be considered a reasonable means or proportionate measure to achieve the aim of preventing the spread of HIV/AIDS... by driving underground many of the people at risk of infection... [it] would appear to run counter to the implementation of effective education programmes in respect of HIV/AIDS prevention.”<sup>90</sup>

Some countries deny the existence of taboo homosexual practices or claim that they are a Western construct or import, despite studies finding evidence of the extent of men having sex with men.<sup>91</sup> Criminalizing behaviour forces individuals to lead “double-lives” to hide it (particularly in isolated or rural communities where the threat of identification is very real), making access to educational programmes more difficult. Such laws place health workers and educators at the risk of aiding and abetting offences, because they can be accused of promoting or encouraging these sexual acts when in fact, they are merely advising how to carry them out safely. Such a situation tends to create suspicion and hostility between health workers, communities and authorities, rather than an atmosphere of trust and cooperation.

In industrialized countries in particular, laws criminalizing men having sex with men have been repealed because they impede educational programmes and drive those at risk of infection underground. In South Africa the rights of sexual minorities have been enshrined in the 1996 Constitution, and recently upheld in a challenge before the courts.<sup>92</sup> There has been a positive correlation between homosexual men who identify with and are attached to the gay community with its safer sex culture and informal



peer education and support, and the sustained adoption of behavioural change.<sup>93</sup> Religious leaders in some communities have accepted that support of individuals is a fundamental value of faith, regardless of their sexual orientation.

## Sex work or prostitution

Criminal law in the area of prostitution impedes the provision of HIV/AIDS prevention and care by driving people engaged in the industry underground. Such laws should be reviewed with the aim to decriminalize sex work where no victimization is involved, and regulate occupational health and safety conditions to protect sex workers and their clients.<sup>94</sup> Criminalization is stigmatizing and may be reinforced by other laws, such as automatic reductions in penalties for rape of prostitutes.<sup>95</sup> In some countries the human rights of sex workers are violated when they are detained in rehabilitation centres or medical programmes against their will; forced to reside at their place of work or declare their residence in designated areas; unable to be married while registered; required to use special identity cards, or have their papers, such as passports, marked with their occupation.<sup>96</sup>

Victimization, including the use of children as sex workers, and adults who are trafficked or otherwise coerced into the industry should continue to be subject to criminal penalties. Victims should not be prosecuted for their participation, but removed from the industry and provided with medical and psychosocial support services, including those related to HIV. Most prostitution laws are founded on nineteenth century notions of morality and were ineffective then, as now, in suppressing the industry while there continues to be a demand-driven market. By treating sex work as a personal service industry which is neither condemned nor condoned, public health objectives are much more likely to be achieved than under the criminal law.

To be effective in preventing transmission, laws regulating business need to focus on management responsibilities. By removing the fear of prosecution and harassment by police for a range of offences (either engaging in the profession, or associated offences of living off the earning), a freer flow of information and education is encouraged, with workers more likely to present regularly for advice, counselling, testing and treatment. By recognizing the industry through regulation, some of the stigma associated with sex work would be removed. This would make access by health educators with targeted programmes easier, and alleviate 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 which have successfully regulated the sex industry in some jurisdictions include:

- controls on owners/operators should not be so onerous to comply with that a second illegal industry is created, which is inaccessible to health educators.

Controls on land use by premises used for prostitution and on public nuisance protection (e.g. parking by clients, noise and hours of operation) should be analogous to other personal service businesses;

- individual identification or mandatory HIV testing of workers should be prohibited, and also the production or display of any medical certificates/evidence of attendance for HIV testing;
- managers or clients should be prohibited from requiring unsafe sex;
- there should be specific regulation of working conditions (e.g. Codes of Practice) requiring management to supply free condoms and sexual health educational material;<sup>97</sup>
- workers should be classified as employees rather than independent contractors, thus enabling them to obtain industrial benefits (e.g. holiday and sick leave, superannuation and workers' compensation) as well as to contribute through obligations (e.g. taxation);
- special offences should not apply to HIV-positive sex workers. General public health measures for exceptional cases of irresponsible behaviour, regardless of whether it occurs in a commercial context should apply. Targeted offences would criminalize the industry and justify mandatory testing of workers, and would undermine clients' sense of responsibility to use condoms.

In countries where decriminalization is not a realistic political option in the short-term, softer options can be considered. Legislation in some jurisdictions prohibits use of the possession of condoms or of HIV/AIDS education and prevention materials as evidence of the commission of any prostitution-related offence.<sup>98</sup> Without such protection, sex workers often fear carrying condoms on their person (e.g. handbags) or keeping supplies where they work, in case of police raids.

There have been several successful efforts to break the taboos surrounding sexuality, particularly its relationship to HIV/AIDS and the sex industry. Much research has been focussed on participants in the sex industry as “bridge populations,” links between people with high-risk and those with low-risk behaviour. The World Bank cites the example of clients of sex workers who refuse to use condoms, and whose monogamous partners are thereby at risk of HIV infection, to which they otherwise would not be exposed.<sup>99</sup>

Parliamentarians can engage in a productive dialogue with the sex industry. In India the Forum of Sex Workers in Calcutta has lobbied parliamentarians on issues relating to HIV/AIDS and legal recognition of workers' rights. The November 1997 National Conference of Sex Workers was attended by the then Union Home Minister.

#### *Case studies*

There are many successful programmes and projects for making sex work safe through improving conditions and/or diverting people away from the sex industry. Economic development programmes 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. Alternative income-generation schemes can also enable women to leave or be diverted from the industry. These need not be labeled “rescue or rehabilitation” programmes which limit or control women who are not treated as equals. Self-organization of sex workers is a powerful mechanism to promote and sustain safe sex and working conditions by increasing the workers’ control over their work environment.

- EMPOWER<sup>100</sup> is a successful Thai NGO established in 1985 working with sex workers. At its drop-in centres in Bangkok and Chiang Mai educational classes are offered in many areas such as English, creative expression and skills (e.g. sewing, typing), and a nonjudgemental atmosphere is provided for women to gather as a community to change their situation in the industry. HIV/AIDS awareness is incorporated into all projects, including a newspaper addressing workers’ experiences and concerns, outreach work where condoms and information are distributed at workplaces, and projects to enforce workers’ rights.<sup>101</sup>
- A project called TAMPEP spanning four European countries (the Netherlands, Italy, Germany and Austria) reaches 23 different migrants groups from Eastern Europe, South East Asia, Africa and Latin America.<sup>102</sup> Migrant sex workers can be more isolated and less accessible to health information and education programmes. This project provides sex workers with culturally appropriate HIV and STD education, resources and materials, and educates medical and social service providers to respond better to workers’ health needs. Two TAMPEP professionals are provided for each cultural target group. One peer educator is trained to pass on messages and empower her fellow workers. A cultural mediator or negotiator from the migrant community accompanies workers to clinics, providing translations and explanations of health care, as well as vouching for the confidentiality of the service.<sup>103</sup> Language classes are offered for workers to enable them to speak with clients, including the negotiation of sexual practices.
- The STD/HIV Intervention Project in the red-light district of Sonagachi, Calcutta, in India highlights the link between empowerment of workers and prevention of disease. The project was initiated in 1992 by the National AIDS Control Organisation with sponsorship from WHO. Surveys were conducted of sexual practices and STD and HIV infections. Total usage of condoms by sex workers increased from 2.7% in 1992 to 69% in 1993, then 81% in 1995. A decline was found in prevalence of genital ulcers and STDs. Modification

of sexual behaviour could not be achieved merely from a medical intervention, and the project attempted to address wider socioeconomic issues. The basic approach of the project was called “reliance, respect and recognition” and those involved supported the principles of democracy, confidentiality and professionalism.<sup>104</sup> A Health Service Centre was opened in the area to cater for sex workers and their families during the day, and clients in the evening, and free treatment for general as well as sexual health was offered. Peer educators were trained to provide information (e.g. using flipcharts) and communication fieldwork, including condom distribution. Education to promote literacy and legal skills was included after demand by peer educators. Improvement in status and self-esteem made sex workers better able to communicate with each other, their clients and outside contacts, such as law enforcement officers. The health educators became “community leaders, community mobilizers and agents of social change”.<sup>105</sup> A cooperative society was formed in 1995 in order to provide economic and social assistance to sex workers, in the form of savings and loans, social marketing of condoms and programmes for children, e.g. cultural and sporting events, and creches run by older former sex workers.

- In Kenya KVOWRC offers training and loans to women to begin small enterprises, and participate in land purchasing cooperatives.<sup>106</sup> The project also empowers women with knowledge, attitudes and skills to negotiate safer sex, and trains peer educators.

## CHECKLIST – CRIMINAL LAW

1. Does the law provide for the legal operation of needle and syringe exchanges? Are intermediaries (i.e. clients who distribute to third parties) covered by such protection, and is the evidentiary use of needles and syringes with trace amounts of illegal drugs restricted (e.g. immunity for contents of approved disposal containers)?

2. Does the law allow the following sexual acts between consenting adults in private:

- homosexual acts, e.g. sodomy;
- fornication or adultery;
- street sex work; and
- brothel or escort sex work?

3. If sex work is prohibited, or there are prostitution-related offences, is there any exception for HIV prevention and care services (e.g. evidentiary immunity for carrying condoms)?

4. Does the legislation regulate occupational health and safety in the sex industry to require safer sex practices to be:

- practised by clients;
- practised by workers; and
- promoted by owners/managers (including prohibiting the requirement of unsafe sex)?

5. Does the legislation protect sex workers, including children, from coercion and trafficking? Is the object of such protection the removal and support of such workers, rather than criminalizing their behaviour as opposed to those responsible (i.e. owners or intermediaries)?

6. Does the law provide for general, rather than specific, offences for the deliberate or intentional transmission of HIV?

## Prisons

HIV prevalence in prison is often much higher than that in the general community. The risk and actual incidence of transmission is greater because of potentially unsafe behaviour occurring during sex (consensual and coerced), tattooing and needle and syringe sharing, particularly given that a large number of convictions are drug-related. Although such activity is illegal in prisons, and despite attempts to repress it, such behaviour is a reality and should be recognized as such. Prisoners are condemned to imprisonment for their crimes, but they are not condemned to HIV transmission, and prison authorities have a legal duty of care to ensure that this does not occur.

Loss of liberty does not entail loss of human rights, including health. The often closed, overcrowded, violent and unsafe environment in prisons creates a special responsibility for prison authorities to protect the health of prisoners. Mandatory testing of prisoners is not a solution, as this violates their rights and merely creates stigma and lack of confidentiality for HIV-positive prisoners, without providing any protection for prisoners who are not infected. Adequate measures that are respectful of human rights include providing sufficient staffing resources to enable effective surveillance and appropriate disciplinary measures to protect prisoners from rape, sexual violence and coercion.

As stated by UNAIDS to the UN Commission on Human Rights:

**“Prisoners are the community. They come from the community, they return to it. Protection of prisoners is protection of our communities.”<sup>107</sup>**

High turnovers mean that prisoners return to the community after sufficient time to have contracted HIV. They may infect their partners outside who may be unaware of the high-risk behaviour which has occurred in prison.

Services for prisoners as a captive population should be equivalent to the education, treatment, care and support received by the general population.<sup>108</sup> This means providing access to HIV-related prevention information, education, particularly ongoing peer programmes, voluntary (including anonymous) testing and counselling, and the actual means to implement them (condoms, dental dams, water-based lubricant and bleach). Easy access to the means of prevention is critical, as merely making items like condoms available on request (particularly in a way which identifies prisoners, thereby revealing their engagement in illegal sexual behaviour) is not effective.

Consultation with prisoners, warders and their unions is essential to the success of any programme if it is to be acceptable to all parties – one strategy used by legislators in attempting to change the controversial prison environment has been to trial projects to secure support from potential opponents, such as staff. Initiatives around the world include:

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- distribution of 100,000 condoms per month to prisoners by the state government of São Paulo in Brazil;
- a peer education project called “Tereza” by the Social Health and Orientation Nucleus in Rio de Janeiro, Brazil; and
- development of prisoners’ personal and social skills to enhance self-respect and non-recidivist lifestyles, such as the one developed by an NGO called ILPES in San Jose, Costa Rica.<sup>109</sup>

The 1993 WHO Guidelines on HIV Infection and AIDS in Prisons have been implemented sporadically around the world. They have been fully supported in the Netherlands by the National Committee on AIDS Control,<sup>110</sup> and by the Canadian Joint Project on Legal and Ethical Issues,<sup>111</sup> and partially by the Prison Service of England and Wales (it only recommended the distribution of condoms “on prescription”).<sup>112</sup> In Argentina a judge’s critical report in 1987 to the National Court of Criminal and Correctional Appeals later lead to more humane conditions. Another judge ordered the cessation of the practice of chaining AIDS patients in prison hospitals, while the constitutional right of an HIV-infected prisoner to marry his pregnant HIV-infected partner was affirmed by a court in 1992.<sup>113</sup>

Denial of treatment, care, and voluntary participation in clinical research trials can be viewed as a form of inhuman or degrading treatment or punishment.<sup>114</sup> So also can denial of privileges or facilities and segregation solely on the basis of HIV status, as opposed to recalcitrant behaviour, or for the protection of HIV-positive prisoners from harm. Segregation *per se* reveals HIV status to other prisoners and warders, providing an excuse for abuse and threats, which can enhance stigma and isolation even after release to the community. Mandatory testing and unauthorized disclosure of HIV status in prisons should be prohibited. Both mandatory testing and segregation lead to a false sense of security. Segregation is stigmatizing and implies that casual contact with people living with HIV is unsafe, as well as having no impact on violent or dangerous behaviour which is unrelated to HIV status. Segregation can result in the denial of work release and workshop activities, as well as requiring the mixing of maximum and minimum security prisoners in the same unit, for reasons of economy, simply because of its physical location.<sup>115</sup>

In sentencing prisoners for general offences, courts have sometimes viewed HIV as a mitigating factor. Compassionate early release of prisoners with AIDS has been recommended in a number of countries (e.g. Poland and Argentina), on the basis that it should be treated like other life-threatening illnesses.<sup>116</sup>

## CHECKLIST – PRISONS/CORRECTIONAL LAWS

1. Does the legislation provide for access equal to the outside community to the following HIV-related prevention and care services in prisons or correctional facilities:
- information and education;
  - voluntary testing and counselling;
  - means of prevention, i.e. condoms, bleach and clean injecting equipment;
  - treatment, e.g. post-exposure prophylaxis;
  - participation in clinical trials (if available)?

2. Does the legislation provide for protection of prisoners from involuntary acts that may transmit the virus, i.e. rape, sexual violence or coercion?

3. Does the legislation provide for confidentiality of prisoners' medical and/or personal information, including HIV status?

4. Does the legislation not require segregation of prisoners, merely on the basis of their HIV status, as opposed to behaviour?

5. Does the legislation (e.g. sentencing) provide for medical conditions, such as AIDS, as grounds for compassionate early release or diversion to alternatives other than incarceration?

6. Does the legislation provide for non-discriminatory access to facilities and privileges for HIV-positive prisoners?



## Guideline 5: Antidiscrimination and protective laws

States should enact or strengthen antidiscrimination 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.

### Antidiscrimination legislation

Discrimination is one of the most significant human rights abuses in the area of HIV/AIDS. A recent chilling example is the killing of an NGO volunteer who had publicly acknowledged her HIV status on World AIDS Day 1998.<sup>117</sup> Discrimination also impedes the full participation and integration of people living with HIV/AIDS (PLWHAs) in the community. The most effective legal remedy is the enactment of general antidiscrimination legislation which prohibits unfair and irrelevant distinctions being made on specified grounds, including disability. Such laws exist in Australia, Canada, Hong Kong (SAR), New Zealand, South Africa, the USA, and western Europe (e.g. France and the United Kingdom) in various forms, either constitutionally based or under special civil or criminal legislation. It is preferable for HIV/AIDS to be covered by generic legislation so that it is treated like other analogous diseases, and has the benefit of broad-based community lobbying.

The following examples highlight the process of enacting such legislation.

- In Argentina a Commission for Nondiscrimination Against AIDS-infected Persons was created in 1992 by the Under Secretariat of Human Rights of the Ministry of the Interior. This was done in consultation with NGOs, and followed several successful employment law discrimination cases before the courts.<sup>118</sup>
- The *Hong Kong Disability Discrimination Ordinance* was enacted in 1995. The Hong Kong AIDS Foundation worked with other AIDS organizations to form the Coalition of AIDS Organizations Against Discrimination. It lobbied through personal contacts with parliamentarians and public hearings, and developed community campaigns, e.g. presenting a quilt with signatures from supporters to the Legislative Council when the Bill was to be debated. Publicity was generated by PLWHAs writing anonymous personal testi-

monies directed to the public, supported by sympathetic and understanding media coverage. Staff in the Foundation conducted detailed research on the issue of discrimination, including looking at models of legislation from other countries.<sup>119</sup>

- In the USA a coalition to support the *Americans with Disabilities Act, 1990* (ADA) was built by bridging the disability and civil rights movements. Some of the reasons for success in enacting the law included the willingness for political compromises in its content (e.g. instead of banning HIV testing, a two-step process was maintained)<sup>120</sup> and legal precedent – its substantive principles were based on existing case-law under the previous, but narrower, *Rehabilitation Act, 1973* and procedural requirements were drawn from the *Civil Rights Act, 1964*.

The focus of antidiscrimination laws is educative rather than punitive. Agencies which administer the legislation usually operate by investigating and conciliating complaints. Remedies from tribunals or boards which hold formal hearings are available as a last resort when conciliation has not resolved complaints. Jurisdiction is usually circumscribed by the extent of international human rights law. In undertaking to end discrimination on specified grounds, states are obliged to protect individuals from discrimination not only by public authorities, but also the private sector and private individuals in public activities. Although private acts, such as friendships, are not covered, such laws provide an environment to sensitize public opinion, expose stereotypes, and changes attitudes and behaviour.

The coverage of such legislation should be as wide as possible to cover people living with HIV/AIDS (particularly as HIV can be asymptomatic),<sup>121</sup> those suspected or presumed to be infected, such as members of vulnerable populations, and their associates or family. The areas to be covered should include:

- health care;
- employment;
- welfare and social security benefits;
- education and training;
- sport;
- associations and clubs;
- accommodation;
- trade unions and qualifying bodies;

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- access to transport;
- superannuation and insurance; and
- provision of goods and services.

Both direct and indirect discrimination need to be covered by such legislation. Direct discrimination occurs where a person treats another person less favourably than a third person would have been treated in comparable circumstances, or attributes characteristics which are thought to relate generally or be generally imputed to people of a particular status, i.e. stereotypes. Indirect discrimination occurs where unreasonable conditions or requirements, such as mandatory HIV testing, are applied which a substantially higher proportion of persons of a different status must be able to comply with than persons of the same status as the person claiming to have been discriminated against.<sup>122</sup> Loopholes in the employment area which must be guarded against include: the coverage of vicarious liability, so that employers, principals and partners are covered by the legislation; and the “comparability problem” through which discriminators can argue that the disability created a difference in the way a person performed a task<sup>123</sup>.

Some jurisdictions have outlawed HIV/AIDS vilification.<sup>124</sup> Vilification is the making of statements based on stereotypes of a group that brings members of it into hatred, ridicule or contempt.

Another innovative feature of antidiscrimination legislation is enabling “affirmative action”, so that, for example, a community group may give preference in employment to HIV-positive people because they are members of a protected class which has been subjected to general discrimination.

Evidentiary standards of proving discrimination should be addressed by legislation. Making HIV/AIDS disability only one of several reasons for doing a discriminatory act should be sufficient to ground a case. Also, making a causal connection, rather than proof of intent, between the discriminatory conduct and HIV/AIDS/disability should be a requirement to found a case under such legislation.

Effective administrative procedures for lodging complaints are essential. There should be independent, informal and quick avenues for redress, such as human rights commissions, which have special procedures for fast-tracking cases where the complainant is terminally ill; otherwise respondents can seek to delay proceedings until the complainant dies. Special protections should exist to allow representative complaints, so that the case does not lapse when the complainant dies, and also to enable community groups or unions to lodge complaints on behalf of their constituents. Remedies should exist for systemic discrimination by respondent agencies, rather than simply for individual cases which have limited application. Broader investigative

powers by the agency administering the legislation (i.e. a national human rights institution) would be necessary to address these wider issues. As well as taking time and energy from complainants, proceedings can result in publicity and victimization, so legislation should make it possible for complainants to use pseudonyms to protect their identity.

Most antidiscrimination legislation contains exceptions and exemptions, and it is important that these are narrowly framed to avoid the purpose of the legislation being thwarted. Employment is one main area of contention. A requirement should exist which states that the person be able to perform the inherent requirements of the job,<sup>125</sup> and an obligation should be placed on employers to provide reasonable accommodation, but not to the extent that unjustifiable hardship is caused. The use of the term “reasonable” requires an objective rather than subjective test. Very wide exceptions found in other legislation can be problematic, as this could authorize discriminatory measures such as premarital testing. In the area of superannuation and insurance, the only exception should be on the basis of reasonable actuarial data, so that HIV/AIDS is not treated differently from other analogous medical conditions.

## CHECKLIST – ANTIDISCRIMINATION LEGISLATION

1. Does the legislation provide for protection against discrimination on the ground of disability, widely defined to include HIV/AIDS?

2. Does the legislation provide for protection against discrimination on the ground of membership of a group made more vulnerable to HIV/AIDS, e.g. gender, homosexuality?

3. Does the legislation contain the following substantive features:

- coverage of direct and indirect discrimination;
- coverage of those presumed to be infected, as well as carers, partners, family or associates;
- coverage of vilification;
- the ground complained of 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, employment, education, accommodation)?

4. 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?

5. Does the legislation provide for the institution administering the legislation (e.g. human rights commission, or ombudsperson) to have the following functions:

- education and promotion of human rights;
- advising government on human rights issues;
- monitoring compliance with domestic legislation and international treaties and norms;
- investigating, conciliating, resolving or arbitrating individual complaints;
- keeping data/statistics of cases and reporting on its activities?

## Discriminatory impact of laws affecting vulnerable populations

The disproportionate impact of HIV/AIDS on vulnerable populations makes the improvement of their legal status and realization of their human rights critical if an effective response to the epidemic is to be achieved. Vulnerable populations include women, children, indigenous populations, people with disabilities, and men who have sex with men. Without full respect for human rights, vulnerable populations are not in a position to avoid infection because they either do not receive prevention education and information, or cannot act on it, and when infected are disempowered to cope with the impact. Legal systems have served in some countries as the source and reflection of systematic discrimination. In some countries, holding of a national inquiry into the human rights of a particular population has been a useful sensitization or lobbying tool. Often these inquiries have been convened by an independent and well-respected public figure, such as a human rights commissioner. Guideline 8, which discusses the need for the promotion of a supportive and enabling environment for vulnerable groups beyond law reform, should also be referred to.

### *Women*

In relation to women, laws need to be reviewed and reformed to ensure equality of treatment in respect of:

- property – ownership, inheritance, entering into contracts, obtaining finance and credit;
- marital relations – entering into marriage, initiating separation and divorce proceedings, equitable division of assets and retaining custody of children upon separation and divorce;
- equal remuneration of men and women for work of equal value;
- facilitating the fulfillment of family responsibilities by workers, e.g. provision of maternity and paternity leave, and quality childcare; and
- protection from sexual violence and harassment, including legal recognition of marital rape (e.g. Peru)<sup>126</sup> and prohibition of genital mutilation (e.g. Côte d’Ivoire).

Special protective laws may need to be enacted if administrative practice does not ensure:

- equal access to sustenance, education, employment and economic opportunity; and
- reproductive and sexual rights, including:

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- independent access to reproductive and STD health information and services
- free choice and means of birth control, such as abortion
- determining the number and spacing of children
- demanding safer sex practices, and
- refusing sexual relations.

Education of women about their legal rights in these areas is equally important for them to be able to protect themselves in sexual and other relationships, by asserting their rights in practice.

#### *Children*

Children in some countries are not only denied special protection guaranteed under international human rights law, but also basic rights exercised by adults. Laws should be reviewed and reformed if necessary to ensure adequate protection against HIV transmission in the following areas:

- freedom from trafficking, prostitution, sexual exploitation and abuse, with provision of rehabilitation, rather than penalization, of victims – some countries have given such legislation, relating to the exploitation of children for sexual purposes, extraterritorial operation to extend the reach of relevant provisions;
- the right to receive information and education targeted to children on avoidance of infection and how to cope if infected both inside and outside school;
- access to voluntary testing and counselling with the consent of the parent/guardian or child, in accordance with his or her evolving capacities;
- special protection and assistance if deprived of family environment, including alternative care, protection and adoption, particularly for those orphaned by AIDS; and
- involving and empowering children in the design and implementation of programmes for them.

The rights to nondiscrimination and privacy are important in decisions regarding custody, fostering or adoption – the best interests of the child are paramount in such cases, but should not be used as a pretext for mandatory testing. HIV status should be confidential, but if the HIV status of the child or parent is already known, it should be treated like other analogous medical conditions.

*Sexuality*

There is no justification for the discriminatory difference in ages of consent for homosexual and heterosexual sex, or between males and females. The age of consent should be consistent, regardless of sexual orientation or gender.<sup>127</sup> The age of consent to marriage is also important because early marriage of female children can be prejudicial to health.

Some jurisdictions<sup>128</sup> have given legal recognition to nontraditional domestic relationships, to include homosexual<sup>129</sup> as well as heterosexual de facto arrangements.<sup>130</sup> Such legislation can cover issues such as automatic rights of inheritance, superannuation and insurance rights, legal aid, possible tax and social security advantages and liabilities. The rationale, apart from equality of treatment to that of a married couple, is that raising self-esteem increases commitment to behavioural change, as well as lessening the financial burden of HIV/AIDS legal problems, e.g. intestacy, property settlements and superannuation/life insurance benefits. Married women in some countries are also denied these rights because of their subordinate legal status.

Policing practices in relation to assaults against gay men have been found to be discriminatory in some countries, i.e. complaints are not taken seriously or are ignored, and perpetrators are implicitly condoned for their violation of the law. As well as being a denial of the human right to security of the person, this discriminatory non-enforcement of the law increases the vulnerability of gay men to sexual violence and can contribute to undermining of self-esteem necessary to enable the negotiation of safer sex.



## CHECKLIST – EQUALITY OF LEGAL STATUS VULNERABLE POPULATIONS

1. Does the law ensure the equal legal status of men and women in the following areas:

- ownership of property and inheritance;
- marital relations, e.g. divorce and custody;
- capacity to enter into contracts, mortgages, credit and finance;
- access to reproductive and STD health information and services;
- protection from sexual and other violence, including rape in marriage;
- recognition of de facto relationships;
- prohibition of harmful traditional practices, e.g. female genital mutilation?

2. Does the legislation prohibit mandatory testing of targeted or vulnerable groups, such as orphans, the poor, sex workers, minorities, indigenous populations, migrants, refugees, internally displaced persons, people with disabilities, men who have sex with men, and injecting drug users?

3. Does the law require children to be provided with age-appropriate information, education and means of prevention?

4. Does the law enable children and adolescents to be involved in decision-making in line with their evolving capacities in regard to:

- consenting to voluntary testing with pre- and post-test counselling;
- access to confidential sexual and reproductive health services?

5. Does the law provide protection for children against sexual abuse and exploitation? Is the object of such legislation the rehabilitation and support of survivors, rather than further victimizing them by subjecting them to penalties?

6. Does the law provide an equal age of consent for heterosexual and homosexual acts? Does the law recognize same-sex marriages or domestic relationships?

## Privacy

Because of the existence of discrimination, the sensitivity surrounding HIV-related information is higher than for other medical data. The type of information includes: health records; personnel files; applications for benefits, e.g. social security; court and police records; and counselling files. HIV-related personal data should be widely defined to include information that identifies an individual or raises a suspicion that the person:

- is or may be infected with HIV, or have AIDS or any AIDS-related condition;
- has undergone an HIV test;
- is or has received therapy that suggests that the person may have HIV/AIDS;
- has been asked or advised to have an HIV test, or received counselling about testing;
- has engaged in behaviour that could put the person at risk of contracting HIV; or
- is or was an associate of another person with HIV/AIDS, e.g. a partner.

There is a need to enact general confidentiality and privacy laws that adequately cover HIV/AIDS. In some countries medical data are specifically regulated – e.g. in Hungary the *1997 Law of the Protection and Handling of Health-Related Data* includes HIV/AIDS in a category of infectious diseases where reporting to the public health authority is generally without personal data (although it may be required in certain circumstances). Data protection or privacy legislation exists in several countries, such as Australia, Canada, New Zealand and those in Western Europe. It is enforced by the setting up of independent agencies such as privacy commissioners, to receive and investigate complaints, with power to award compensation where conciliation fails. It is preferable that such laws cover the private sector as well as the public sector, because of the huge variety of records which are HIV-related.

The privacy principles covered under such laws include:

- when personal information should be collected by agencies covered by the legislation (i.e public and/or private, depending on the national law), such as when it is necessary to exercise a lawful function;
- the type of security measures required to protect personal data, particularly where it is computerized;
- when individuals are entitled to see their own records, and make amendments to ensure that they are accurate, relevant, complete and up-to-date;

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- the use, with adequate protections, of information for medical or social research;
- the purpose to which this personal information can be used and disclosed, apart from the original reason for which it was obtained. The exceptions to this principle relating to original purpose are:
  - informed consent
  - special legal requirement or court order, e.g. criminal proceedings relating to HIV transmission (see above)
  - partner notification ( see above).

In either case (the original purpose or other purposes of use and disclosure), the benefits or potential benefits resulting from use or disclosure should be likely to outweigh the harms or potential harms.

In Canada the Privacy Commissioner published a report in 1989 with guidelines for the strict regulation of the collection, storage and use of HIV/AIDS-related personal information. This approach was also followed by Canada's largest province, Ontario, in 1990.<sup>131</sup> Guidelines were also issued in Australia in 1992,<sup>132</sup> but have only been legislatively implemented in one state (the *Tasmanian HIV/AIDS Preventative Measures Act 1993*).

In the Netherlands the Penal Code provides for proceedings (which may even be taken on behalf of a deceased patient) on the basis of violation of professional secrecy.<sup>133</sup> A libel suit was won in 1987 by the parents of a woman who died of AIDS in Japan, in a case where the media had identified her with photos and reported that she had worked as a prostitute.<sup>134</sup> The European Court of Human Rights has found that the publication of a person's identity and HIV status can violate the right to respect for private and family life.<sup>135</sup> Other measures apart from legislation can help create a culture that is respectful of privacy. Professional bodies, e.g. those of health carers and journalists, should be enabled to discipline breaches of confidentiality<sup>136</sup> or unreasonable invasion of privacy as professional misconduct under specially drafted codes (see Guideline 10). In the case of legal proceedings, it should be possible for any court to issue privacy or confidentiality orders protecting identity in cases where the HIV status of an individual is likely to be raised.<sup>137</sup> In some countries evidence laws require rape victims to disclose their HIV status<sup>138</sup> to establish cases of aggravated assault.

## CHECKLIST – PRIVACY/CONFIDENTIALITY LAWS

1. Does the legislation provide for general privacy or confidentiality protection for medical and/or personal information, widely defined to include HIV-related data?

2. Does the legislation prohibit unauthorized use and disclosure of such data?

3. Does 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 are:

- accurate;
- relevant;
- complete;
- up-to-date?

4. Does the legislation provide for the independent agency administering the legislation (e.g. privacy or data protection commissioner) to have the following functions:

- education and promotion of privacy;
- advising government on privacy issues;
- monitoring compliance with domestic legislation and international treaties and norms;
- investigating, conciliating, resolving or arbitrating individual complaints;
- keeping data/statistics of cases and reporting on its activities?

5. 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)?

6. Does public health legislation provide for reporting of HIV/AIDS cases to public health authorities for epidemiological purposes with adequate privacy protections (e.g. use of coded rather than nominal data)?

## Employment law

Some areas of concern in employment law are: that workers with HIV/AIDS are not subjected to unfair discrimination; that appropriate prevention measures are available for occupational health and safety reasons; and that adequate compensation is available for workers who are occupationally infected. Employees with HIV/AIDS are able to lead reasonably long and productive lives, particularly with recent advances in anti-retroviral treatments in industrialized countries. Attempts to prematurely exclude people living with HIV/AIDS from the workforce are unfair and a breach of human rights. They are also potentially uneconomic as they can arbitrarily exclude the most qualified person from a position and create an unnecessary burden on the social security system.

Risks to public safety by deterioration in the ability to perform certain tasks owing to AIDS dementia complex, e.g. among pilots, are best excluded by general practical tests for neurological and spatial functioning, to determine whether impairment is due to various causes (e.g. substance abuse, stress/fatigue, or brain tumour) other than HIV. There should be no legal obligation<sup>139</sup> on employees to disclose their HIV status to employers, although exceptional cases involving irresponsible behaviour can be dealt with under provisions in public health legislation. The performance of invasive procedures by HIV infected health-care workers is adequately regulated by their treating clinician, specially formed expert panels, or professional registration boards on an individual case-by-case basis. When HIV-positive employees are unable to work owing to illness, then policies applicable to analogous diseases should apply (e.g. the taking of sick leave).

Laws should be reviewed to ensure that they contain the following protections:

- prohibition of HIV screening for employment (i.e. recruitment or dismissal from continuing employment), promotion, or training purposes. Antidiscrimination laws and actions for unfair dismissal should be sufficient, but some jurisdictions have specifically prohibited HIV testing.<sup>140</sup> It may, however, be in an employee's interests to have baseline tests voluntarily performed immediately after a workplace exposure, e.g. a needlestick injury, to assist in the preparation of a possible compensation claim.
- protection from discrimination where the HIV status of a worker is known or questioned by coworkers, clients and unions (e.g. the duty to fairly represent all members, as enforced by legislation in the USA to prevent racial discrimination), as well as employers. This would be through antidiscrimination legislation, with the duty on employers to reasonably accommodate workers with disabilities or creation of a new discrimination ground of occupation, where workers are stigmatized because of the industry they work in – such as work which society may adversely associate with HIV because of the occupational risk of transmission, e.g. health care, sex work and possibly the funeral industry;

- confidentiality of medical information, including HIV status, particularly during the course of making a compensation claim (e.g. enabling protection of identity during court or tribunal proceedings);
- access to general information and education programmes, including provision of condoms, relevant counselling (e.g. recommending safer sex after a needlestick injury to prevent possible secondary infections, and explaining the benefits and risks, i.e. toxicity, of taking zidovudine as a prophylaxis)<sup>141</sup> and referral services;
- adequate coverage for occupational transmission of HIV, including recognition of the long latency period of infection;
- adequate access to health care and other sources of income support when the employee is no longer able to work, e.g. social security, insurance, superannuation, termination, sickness and death benefits; and
- the clarification of employers' obligations in daily work practices to take reasonable care of the health and safety of employees by the development of legislative codes for industries where there is a specific risk of occupational infection, and generally, e.g. first aid practices.

A best practice example of the last point is the development by Worksafe Australia (the National Occupational Health and Safety Commission) of the Code of Practice on HIV/AIDS for Health Care Workers and Others at Risk in 1993. The Occupational Safety and Health Administration in the USA has developed similar regulations. They provide national, uniform standards on universal infection control precautions (i.e. avoiding recapping of used needles by hand, the proper disposal of used needles, and the covering of skin, especially where it is not intact). Workers and institutions must follow them to protect against HIV transmission. The existence of these standards can prevent the use of occupational health and safety grounds as a pretext for discriminatory HIV testing. Such codes or regulations should replace out-dated or inappropriate public health laws which ban HIV-positive people from working, or even being clients, in certain workplaces, e.g. those concerning food-handling, drug manufacture and skin penetration, i.e. tattooing, body piercing, acupuncture, depilation and hair restoration.

## CHECKLIST – EMPLOYMENT LAW

1. Does the legislation prohibit HIV screening for general employment purposes, i.e. appointment, promotion, training, and benefits?

2. Does the legislation prohibit mandatory testing of specific employment groups, e.g. military, transport workers, hospitality/tourist industry workers, and sex workers?

3. Does the legislation require implementation of universal infection control measures, including training and provision of equipment in all settings involving exposure to blood/body fluids, e.g. first aid, and health care work?

4. Does the legislation require provision of access to information and education about HIV/AIDS for occupational health and safety reasons, e.g. workers travelling to areas of high incidence?

5. 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 where workers are no longer able to work?

6. Does the law provide for confidentiality of employees' medical and personal information, including HIV status?

7. Does workers' compensation legislation recognize occupational transmission of HIV?

## Guideline 6: Regulation of goods, services and information

States should enact legislation to provide for the regulation of HIV-related goods, services and information, so as to ensure widespread availability of qualitative prevention measures and services, adequate HIV prevention and care information and safe and effective medication at an affordable price.

### Regulation of therapeutic goods and services

While there is no cure or vaccine for HIV, the most effective measure to control the epidemic is through education and information on the ways and means of preventing transmission. Legislation has been enacted in some countries to ensure the widespread availability and quality of HIV-related goods and services. Many countries, such as Canada and South Africa, have created fast-tracking mechanisms for obtaining approval by authorities for therapeutic goods applications in special situations, such as HIV/AIDS treatments.

While laws so far have had a limited impact on market pricing, there is scope for review of duties, customs and value-added taxes to make them more affordable. In the case of condoms, governments in some countries supply them for free, or merely charge a notional fee.

#### *Testing kits*

Laws and regulations in the area of therapeutic goods can safeguard the standard (i.e. accuracy and reliability) and use of HIV test kits (e.g. only by medical personnel in approved laboratories) by having an authorization process and health authority to enforce it. There are dangers in authorizing home and/or rapid HIV test kits because of: the loss of counselling opportunities, both in the areas of behaviour modification and to cope with the impact of a positive result; the potential for misinterpretation (e.g. need for confirmatory testing) of results; loss of valuable epidemiological data; and inappropriate and secret uses, e.g. by employers or insurers. If governments permit the use of home and/or rapid test kits on the market for reasons such as promoting anonymous testing, then these adverse consequences need to be addressed. The establishment of legal and social advice and support services (e.g. accessible from the home by telephone or computer) to protect individuals from abuses would be one method.



#### *Condoms*

High quality and low cost condoms should be as widely available as possible because of their use as a barrier to HIV and STD infection, and their central role in safer sex education programmes. Social marketing of condoms is enhanced by wider accessibility in commonly used sites, such as night clubs, restaurants, airports and other transport stations, toilets, university or high-school dormitories, supermarkets, pharmacies and other shops such as newsagents. Other distribution methods, which have the additional value of protecting anonymity include mail order, Internet and vending machines. Such marketing can reach clients of sex workers, reinforcing intervention programmes, such as the 100% condom use programme in Thailand, targeting the commercial sex industry. Widespread marketing can complement integrated family planning and reproductive health programmes which do not usually reach young sexually active people. Religious leaders should be consulted in designing such programmes otherwise insensitivity can lead to bans on media advertising of condoms, as occurred in Uganda between 1991 and 1995.

Legislative barriers which restrict the distribution, promotion, advertising or sale of condoms should be reviewed, and if necessary, repealed (e.g. as occurred in 1987 in Belgium and France). A similar review of impediments to the availability of other products that prevent the transmission of HIV, such as sterile needles and syringes, and bleach has been recommended in relation to injecting drug use (see above).

Condom failure is usually due to noncompliance with instructions about proper use, which can be overcome with education and information campaigns, or product failure, i.e. breakage or leakage. Legal quality control should be assured by the enforcement of the International Condom Standard<sup>142</sup>, by monitoring authorities conducting ongoing inspection, product testing, collection of adverse reports and random sampling in the factory and market. Consumer protection legislation should be reviewed, and if necessary amended, to ensure that sub-quality products, e.g. those that are out of date, are compulsorily recalled throughout the supply chain. Warnings are necessary about the use of condoms with oil- or petroleum-based rather than silicone or water-based lubricants, and also the lack of protection from HIV with natural membrane condoms (e.g. made of lamb skin, for people who are allergic to latex) if they are not banned.

#### *Treatments*

Consumer protection, product liability or therapeutic goods legislation should also ensure that fraudulent claims regarding the quality, safety and efficacy of HIV-related drugs, vaccines and medical devices are prohibited and effectively enforced. This should not adversely impact on the availability of alternative, traditional and herbal remedies that make general claims about improving the functioning of the immune system.

The issue of price is particularly problematic in developing countries where the cost of safe and effective treatment drugs, particularly antiretroviral triple therapy, is a significant barrier to accessibility (see Annex A). This has recently been an area of great focus:

- In Costa Rica the government is obliged, through a Supreme Court ruling, to provide free HIV/AIDS treatment under its national health system.
- Similar rulings under the Constitution or by enactment of special laws have been made in Albania and Brazil<sup>143</sup>.
- In Spain an NGO called Fundación AntiSida de España (FASE) has been working for five years to have AIDS, and now HIV infection, to be considered a “chronic illness” under the law. This has enabled patients to buy non-antiretroviral medications for 10% of their cost since December 1995 (antiretroviral medications are currently free). FASE also campaigned to increase access to triple therapy, and in 1996, a resolution was passed in parliament encouraging the Ministry of Health to give treatment to anyone needing it.<sup>144</sup>
- In 1996 eight Argentine NGOs presented a petition for state protection under Article 43 of the Constitution against the Ministry of Health. The courts have consistently found that the Ministry is under a legal obligation to provide full treatment, including antiretroviral drugs, and care free of charge to people living with HIV/AIDS who are unable to pay for them and are not covered by social security.<sup>145</sup>

In some countries free treatment is available for HIV/AIDS, because it has been classified as an infectious disease, but this also entails being subject to coercive measures.<sup>146</sup>

## CHECKLIST – THERAPEUTIC GOODS, CONSUMER PROTECTION LAWS

1. Does the legislation regulate the quality, accuracy and availability of HIV tests (including rapid or home testing, if approved)?

2. Does the legislation provide for approval to only be given for sale, distribution and marketing of pharmaceuticals, vaccines and medical devices if they are:

- safe; and
- efficacious?

3. Does the legislation provide consumers with protection against fraudulent claims regarding the safety and efficacy of drugs, vaccines and medical devices?

4. Does the legislation regulate the quality of condoms? Does such regulation include monitoring compliance with the International Condom Standard?

5. Does the legislation ensure the accessibility and free availability of the following prevention measures:

- condoms;
- bleach;
- needles and syringes?

6. Does legislation make HIV/AIDS-related medication affordable, i.e. inclusion in subsidization schemes for certain pharmaceuticals, and lack of duties/customs or tax?

## Ethical research

Protective laws are necessary for the legal and ethical protection of human participants in HIV-related research, such as in the development of safe and efficacious pharmaceuticals, vaccines and medical devices. General and independent local, as well as international, ethical review committees need to be established and their capacities strengthened in order to follow relevant principles, such as:

- the 1947 Nuremberg Code;<sup>147</sup>
- the 1964 Declaration of Helsinki;<sup>148</sup>
- the 1993 Council for International Organizations of Medical Sciences' International Ethical Guidelines for Biomedical Research Involving Human Subjects;
- the 1995 World Health Organization Guidelines for Good Clinical Practice for Trials on Pharmaceutical Products<sup>149</sup> ; and
- the 1997 Council of Europe's Convention on Human Rights and Biomedicine.

The principles of particular relevance to HIV-related research are:

- community consultation in research design, implementation and evaluation, as well as publication and use of research results;
- nondiscriminatory selection of participants, e.g. women, children and minorities;
- informed consent;
- confidentiality;
- equitable access to information and benefits emanating from research; and
- protection from discrimination.

WHO and UNAIDS offer technical assistance in the setting up and continued operation of effective ethical review committees at country level.

The selection of Brazil, Thailand and Uganda as vaccine trial sites (see Annex A) has involved community participation in research programmes. UNAIDS recently held regional community workshops using hypothetical research proposals in each of these countries to develop consensus on ethical guidelines for the conduct of vaccine trials, later agreed at a meeting in Geneva in June 1998. National committees on vaccines in the ministries of health have produced national plans which recognize the need to address ethical issues in Brazil, Thailand and Uganda. In São Paulo, researchers worked with volunteers to facilitate community-building through regular workshops on current gay issues, e.g. gay pride day, and screening films.<sup>150</sup> A particular concern

has been the potential for increased discrimination against minority populations participating in trials.

## CHECKLIST – ETHICAL HUMAN RESEARCH

1. Does the law provide for legal protection for human subjects in HIV/AIDS research? Does the legislation require the establishment of ethical review committees to ensure independent, ongoing evaluation of research?

Do the criteria used in such evaluation include the scientific validity and ethical conduct of research?

2. Does the legislation require subjects to be provided before, during and after participation with:

- counselling;
- protection from discrimination;
- health and support services?

3. Does the legislation provide for informed consent to be obtained from the subjects?

4. Does the legislation provide for confidentiality of personal information obtained in the process of research?

5. Does the legislation provide for subjects to be guaranteed equitable access to the information and benefits of research?

6. Does the legislation provide for nondiscriminatory selection of subjects?

## Rights of education and information

As prevention is a main objective of HIV/AIDS programmes, people need information and need to be educated about the virus and disease, modes of transmission and means of protection. Information about sensitive and private topics such as sex and injecting drug use must be explicit, rather than unhelpfully euphemistic, before people can be in a position to change their behaviour. Widespread use of the mass media is essential. Information can be provided through pamphlets, posters, newspapers, magazines, books, instructions on condom packaging, advertisements, radio, television, films, videos, plays, the Internet, group meetings and assemblies.

Laws in the area of censorship and broadcasting standards may place impediments on such programmes whether directed at the general public or targeted to specific groups whose behaviour makes them vulnerable to infection. Many of these laws originated in the nineteenth century and were aimed at banning “depraved and corrupt” advertisements for contraceptives and cures for venereal diseases, with the underlying judgement that those who broke the moral standard deserved to be punished with unmentionable diseases. Societies must consider the moral or religious values underpinning such laws and decide whether these values outweigh the need to protect members from the transmission of the HIV. Guarantees of the rights to information/education and freedom of expression/association are in international human rights instruments, as well as some national constitutions.

Judgment of what is considered obscene varies according to prevailing social and moral values.<sup>151</sup> Censorship laws should contain a specific exemption for genuine educational or scientific material. In considering community standards it is important that the material is judged according to the audience it is intended for, such as gay men, sex workers or injecting drug users, as opposed to the general public. Effective communication itself requires that an audience is not gratuitously offended or unnecessarily alienated by material, but instead that campaigns be formulated by reference to the groups’ values and attitudes.

Classification of material into different categories of restricted or unrestricted availability occurs in most countries, principally to protect children from inappropriate sexual content. Community representation in the regulatory process, e.g. licensing and registration or formulation of industry codes of practice, can ensure that appropriate standards are reflected in censorship and broadcasting decision-making. The potential for using public broadcasting systems to disseminate HIV/AIDS information and education has not been fully utilized in some countries e.g. the requirement for the free screening of community service announcements in a variety of times, including prime time. Self-regulation of the media industry in the area of advertising can present problems for HIV/AIDS materials that are judged to be offensive or distasteful. It is important that independent and expert HIV/AIDS

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advice is sought by the industry to prevent advertisers inappropriately refusing to broadcast such messages.

Other laws can restrict effective HIV/AIDS campaigns targeted at immigrant and indigenous populations, for example laws which require the use of majority languages in schools. Such laws should be reviewed to ensure that they do not place an impediment to HIV/AIDS campaigns. If necessary they should be repealed, or at least revised to exempt HIV/AIDS educational material.

#### **Freedoms of expression and association**

The illegal nature of activities such as prostitution, homosexuality and drug use can impede the formation of community organizations based on this shared activity. Some governments refuse registration of all nongovernmental organizations, or specifically those which may be critical of government. Such a bar on peer education and support is a significant barrier to an effective response to the epidemic, as well as interfering with human rights. Community acceptance, mobilization and involvement is critical, especially in areas where governments cannot or will not reach owing to lack of trust or understanding by either party. Removal of legal and administrative impediments to associations of communities working in the HIV/AIDS area should be an urgent priority for governments. If wholesale reform is not achievable in the short term, exceptions should be contained in legislative or administrative restrictions on association for health and educational activities.

HIV/AIDS prevention sometimes requires educators to provide information on how to avoid contracting HIV while engaging in illegal behaviour. Educators could be consequently charged with aiding and abetting illegal activities. If reform of the criminal law is not achievable in the short term, exemptions should apply to educators in these circumstances.

Irresponsible and sensationalized portrayal by the media of HIV/AIDS issues has contributed to public hysteria and stigma in many instances. The media needs to be encouraged through education and regulation to be sensitive to HIV/AIDS and human rights issues, including the use of appropriate language and avoidance of stereotypes in the depiction of members of vulnerable groups. Many countries have Press Councils where individuals may make complaints against the media's portrayal of their story. Similarly, there are boards which regulate the conduct of professionals such as journalists. Guideline 10 discusses the need for private sector codes in areas such as the media. The legislative checklist below refers both to Guideline 6 and part of Guideline 10.

## CHECKLIST – ASSOCIATION, INFORMATION, CODES OF PRACTICE

1. Does the law enable the unrestricted movement of people because of their membership of vulnerable groups, e.g. sex workers?

2. Does the legislation enable the unrestricted association of members of vulnerable groups, e.g. gay men?

3. Does censorship legislation contain exceptions for general and targeted HIV/AIDS education and information?

4. Do broadcasting standards contain exceptions for general and targeted HIV/AIDS education and information?

5. Does the law require the following professional groups to develop and enforce appropriate HIV/AIDS Codes of Practice:

- health-care workers;
- other industries where there may be a risk of transmission, e.g. sex or funeral workers;
- media;
- superannuation and insurance; and
- employers (in a tripartite forum involving unions and government)?

6. Are such Codes of Practice required to contain the following elements:

- confidentiality/privacy protections;
- informed consent to HIV testing;
- duty not to unfairly discriminate; and
- duty to minimize risk of transmission, e.g. occupational health and safety standards including universal infection control precautions?



## Guideline 7: Legal support services

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

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Law reform alone cannot achieve realization of human rights – helping individuals to enforce their rights in practice is critical. There are many examples of successful legal services in the HIV/AIDS area. Many are privately, rather than governmentally, funded in both developing and developed countries.

- In Venezuela the Citizen's Action Against AIDS (ACCSI) has been operating since 1987 to provide free legal assistance to people living with HIV/AIDS, their families and associates. It has three lawyers who act in cases and appeals such as in the areas of employment discrimination, medical malpractice or social service problems. One example of public interest litigation is a challenge to the government's requirement of HIV testing for permanent residence applicants. ACCSI works closely with all relevant sectors of society, including government departments (health, finance, justice, prisons, education), AIDS community groups, human rights organizations and private sector corporations.<sup>152</sup>
- The Lawyers Collective, India, is largely self-funded and has been in operation since 1981 to provide legal aid to marginalized groups in public interest litigation. Since the advent of HIV/AIDS it has successfully taken on several high-profile cases, including a constitutional challenge to the *Goa Public Health Act* under which a man was detained because of his HIV status, and an unfair dismissal case (*X v. Y*) in Mumbai. Members of the collective also lobby politicians for reform and have trained a national network of lawyers on HIV/AIDS issues.<sup>153</sup> The Collective recently established a HIV/AIDS unit in Mumbai with the support of the European Commission. It provides legal aid, advice and allied services to people living with HIV/AIDS.
- In the USA there is a very wide array of legal services for PLWHAs, partly because of a strong tradition of pro bono services, many of which have been used as models in other countries. Some are partly government funded under the *Ryan White Care Act*. They include AIDS-specific and non-specific

organizations, general civil liberties, impact litigation (public interest test cases) bodies, and services targeted to vulnerable groups, such as men who have sex with men:

- the Gay Men’s Health Crisis in New York;
  - the Whitman-Walker Clinic in Washington;
  - the AIDS Project, Legal Service in Los Angeles;
  - the Gay and Lesbian Advocates and Defenders in Boston;
  - Lambda Legal Defense and Education Fund, Inc. in several cities;
  - National Lawyers Guild, AIDS Network in San Francisco (a referral service);
  - State AIDS Legal Services Organization, AIDS Legal Referral Panel in San Francisco; and
  - the American Civil Liberties Union in various locations.
- In the UK similar AIDS service organizations exist such as the Terrence Higgins Trust (THT). The THT is the UK’s largest AIDS charitable organization and is partially funded by the Department of Health. It has a small full-time Legal Centre assisted by part-time volunteer lawyers and welfare rights advisers. Advice is given in person, in writing or through a telephone Legal Line operating an evening clinic. Immunity’s Legal Centre, funded by the London Borough Grants Scheme, conducts legal services, including outreach sessions at locations such as the London Lighthouse, Landmark and Body Positive Centre.

To increase the number of cases that can be handled many of these services have devised mechanisms, such as do-it-yourself legal documents (e.g. wills), pamphlets on specific issues (e.g. employment, housing, superannuation, immigration, debt, etc.), legal services directories,<sup>154</sup> advocacy training handbooks for volunteer lawyers<sup>155</sup> and paralegals,<sup>156</sup> benchbooks for judicial officers<sup>157</sup> and general texts.<sup>158</sup>

## (C) Promotion of a Supportive and Enabling Environment

### Guideline 8: Women, children and other vulnerable groups

States should, in collaboration with and through the community, promote a supportive and enabling environment for women, children and other vulnerable groups by addressing underlying prejudices and inequalities through community dialogue, specially designed social and health services and support to community groups.

This Guideline is the most difficult to implement because its impact is so far-reaching. Empowering vulnerable populations to deal with HIV/AIDS by improving their social and legal status is a huge but necessary undertaking, requiring administrative and legislative measures in most facets of life. Vulnerability depends on the legal, social and economic conditions, as well as the nature of the epidemic in each country. However, the groups most commonly affected are women, children, religious or ethnic minorities, indigenous people, migrants, refugees, internally displaced persons, people with disabilities, economically disadvantaged groups, itinerant workers, gay men, injecting drug users and sex workers. In order to develop targeted programmes, there is value in governments and communities identifying these groups at national level, as long as protections are guaranteed to allay fears of stigmatization and possible coercive measures. Involvement of vulnerable communities is important for many reasons, including the fact that active involvement in prevention, care and support programmes helps ensure their relevance and effectiveness, as members have greater understanding of changing needs and factors influencing risk and vulnerability.

An expanded response to HIV/AIDS focuses on more than individual risk-taking behaviour. The complex interaction of the following factors may create or reinforce individual, and therefore collective, vulnerability: personal, e.g. sexual history; the quality and coverage (i.e. accessibility, appropriateness, and cost) of services and programmes aimed at prevention, care, social support and impact-alleviation; and society, e.g. cultural norms, laws, beliefs or social practices. There is a danger in over-simplifying the vulnerability paradigm,<sup>159</sup> e.g. in some developing countries higher infec-

tion rates have been found in higher educated groups, especially men whereas, educating young women has usually improved prevention programmes.

## Gender and reproductive rights

Apart from increased biological susceptibility to infection, women's subordinate status in many countries limits opportunities to be informed about HIV/AIDS making them more vulnerable to infection and impairing their ability to deal with possible consequences of infection which require care and support (e.g. violence and abandonment by family). Systematic discrimination in all facets of life, but particularly, education, health care and employment, disproportionately increases the risk of women becoming infected. Education and prevention programmes are hindered where women lack the skills to understand, or the capacity to act upon, the information contained in them. Women sometimes cannot negotiate safer sex or leave their partners because of social and legal norms, and economic dependency. Norms that promote motherhood as the ideal form of self-worth and identity for women increase vulnerability to HIV, and constrain reproductive choices for HIV-positive women. Double standards about chastity and fidelity means that many monogamous married women have been powerless to avoid infection by their husbands.

Sexual and other violence directed at women (including within marriage), as well as traditional practices such as female circumcision and infibulation, are not legally prohibited in some countries. Such acts, or even fear of the threat of violence, cause increased risks of HIV infection, as well as physical and emotional harm to women. Guideline 6 discussed the discriminatory impact of laws, such as those which prevent women from owning land or property, or which perpetuate inequity by failing to provide equal remuneration for work of equal value.

### *Improving women's status*

The disproportionate rates of illiteracy and poverty in women that fuel the epidemic have been targeted by several empowering projects.

- In Nepal a three-year AIDS community-based prevention programme was funded by the American Foundation for AIDS Research.<sup>160</sup> Education and income-generating projects have been successful interventions in the Badi, Danuwar, Tamang and Tharu communities, which have traditionally been highly discriminated against. The projects attempt to address the low status of women by leadership training, rights advocacy and literacy, integrating HIV information in general health classes. Innovative methods have been used such as street drama, and non-formal education.
- In Zambia women fish traders have been supported by a UNAIDS project to form a cooperative for obtaining interest-free loans. This will lessen the need

to exchange sex with fishermen and truck drivers who control their access to fish and transport.<sup>161</sup>

Similar education and microfinance projects can be found around the world, but often the aim is simply to improve women's access to economic resources, rather than being specifically concerned with HIV/AIDS prevention or impact alleviation (although it is possible that they do have an impact).

Setting up institutional organizations to address gender-related issues has also proved successful. The three main components to a successful organization are: political commitment publicly stated by the organization's leaders; a participatory approach to developing mechanisms to address gender; and incorporating gender across programmes, rather than in separate units, to avoid marginalization.<sup>162</sup> Some countries have established institutions to promote the rights of women, such as:

- Brazil – the National Council on Women's Rights;
- South Africa – the Office of State for Women;
- Colombia – the Directorate for Gender Equity;
- Haiti – the Ministry of Women's Affairs and Women's Rights;
- Jamaica – the Commission on Gender and Social Equity;
- Peru – the Women's Rights Commission; and
- the Philippines – National Commission on the Role of Filipino Women.

In South Africa gender units have also been established in several Ministries, as well as an independent gender commission to monitor progress of the national gender framework. Having gender as a cross-cutting theme has been an element of successful national AIDS programmes. In Uganda gender has been central to the multisectoral approach of the AIDS Commission. In Malawi the UN Gender Working Group issued a UN Joint Gender Policy Statement to support the National Policy Framework for Poverty Alleviation programme.<sup>163</sup>

#### *Legislative reform*

Legal reform is a key component of campaigns to improve the status of women. National inquiries into the impact of current laws on women have been held in countries such as Kenya (a task force established in 1993 and headed by Judge Effie Owuor)<sup>164</sup> and Malawi. Reproductive rights are explicitly guaranteed in some countries' constitutions such as Chile, Mexico and South Africa. In Sri Lanka a Women's Charter approved by the government recognizes women's' rights to control their reproductive lives. Legal reform in the area of inheritance has had some success in Malawi, Tanzania and Zambia. In Uganda an NGO called ACORD works with the

Ugandan Women Lawyers Association on the issues of land rights and inheritance, so that women can retain property after the death of their spouse from AIDS.<sup>165</sup> An NGO called Women in the Law and Development in Africa is translating such laws and training paralegals to teach women about their rights.<sup>166</sup> In India, the Asian Centre ran a training course on the contribution of women in the development process for Organization Research (ACORD) to sensitize people working with grassroots organizations in low-income areas. Evaluation of the project showed increased knowledge, confidence and self-esteem of participants, with the module on legal rights having the greatest impact on changing attitudes and perceptions.<sup>167</sup>

The United Nations Population Fund (UNFPA) has estimated that there are 130 million women living with the consequences of female genital mutilation (FGM).<sup>168</sup> The International Conference on Population and Development (ICPD) in Cairo declared that female genital mutilation was a violation of human rights and a lifelong threat to women's health. Apart from the risk of using unsterilized instruments, scarification from female genital mutilation improves the efficacy of HIV transmission through increased trauma and tearing during sex and childbirth. Some countries have responded by prohibiting the practice, such as Côte d'Ivoire. The campaign to eliminate female genital mutilation, which 2 million girls are subjected to yearly, has been sensitively handled by some NGOs:

- in Kenya the women's organization Maendeleo ya Wanawake has developed community-based programmes;
- in Uganda the Reproductive, Educative and Community Health programme has shown that practices can change without compromising values;<sup>169</sup>
- in 1995 the Ghanaian Association on Women's Welfare succeeded in its campaign to criminalize female genital mutilation, and continues to conduct community education to end such practices;
- in Nigeria a multisectoral working group including representatives from NGOs, the Ministries of Health and Justice, and international agencies developed a national policy and plan of action to end female genital mutilation.<sup>170</sup>

As well as enactment of law, enforcement is an important issue. Many countries are attempting to reduce domestic violence through public education campaigns (e.g. Brazil), legislation (e.g. Bolivia, Costa Rica, Ecuador and Panama), and forging links between police and women's NGOs (e.g. Nicaragua). In some countries (e.g. India) women police officers work in domestic violence and sexual assault units to make the units more sensitive and accessible to victims.

#### *Health care*

Service integration of HIV/AIDS prevention and STD diagnosis and treatment within reproductive and family planning services is an important issue. Norms such as body modesty and preferential health care for men are barriers to women's access to health services. Undiagnosed STDs with consequent genital inflammation and lesions increase the efficacy of HIV transmission.<sup>171</sup> A best practice example of a gender-sensitive service is Sociedade Civil Bem-estar Familiar do Brasil (BEMFAM) which approaches clients with a holistic perspective of overall health and well-being.<sup>172</sup> Two similar clinics operate in Bolivia. The Casa de la Mujer clinic offers reproductive health services, legal advice, psychological care, education, nutrition, preventive health, citizenship and labour training. The Centro de Informacion y Desarrollo de la Mujer (CIDEM)/Kumar Warmi clinic offers integrated free or low-cost services addressing biological, legal, psychological and sociocultural aspects of women's health.<sup>173</sup>

#### *Men as partners*

There has been increasing recognition that in order to influence gender relations, men must also be targeted. The Panos AIDS Programme is of the view that men drive the global epidemic:

“...because men have more sexual partners than women, because men tend to control the frequency and form of intercourse and because women are physiologically more susceptible to the virus, it is men's behaviour which determines how quickly, and to whom, the virus is spread... Such behaviour does not mean that men are 'responsible' for the AIDS epidemic. Men are also at risk, since they cannot transmit the virus to others unless they contract it first themselves.”<sup>174</sup>

The focus of the seventh international conference of the Society of Women Against AIDS in Africa held in Dakar, Senegal, in December 1998 was the enhancement of men's participation. The Dakar Declaration from the Conference called for commitment and increased dialogue between men and women, and urged political leaders to “tirelessly broadcast messages on the seriousness and urgency of the AIDS problem”. In Jaipur, India, a pilot project involving truck drivers and their spouses has used the dialogue approach to communication between men and women – its positive results have facilitated the project's expansion to other sites.<sup>175</sup> An example of an innovative project can be seen in Jamaica where an alliance called Fathers Inc. has been established to counter negative stereotypes of men and provide counselling to teenage youths about parenting, HIV/AIDS and STDs.<sup>176</sup>

## Children and young people

Working in partnership with young people is the best hope of containing the epidemic. As well as being a resource to tap into for idealism and energy, young people's ideas and values are not always set, and they can be more willing to question and change social norms and behaviour than adults.<sup>177</sup> Their vulnerability is underlined by the fact that more than half of people living with HIV/AIDS were infected before they were 25 years old. Factors increasing vulnerability include poverty, violence, lack of skills, and harmful social norms such as machismo and early sexual debut (often forced, exploited and dangerous).<sup>178</sup> High rates of teenage pregnancy and sexually transmitted diseases indicate the existing levels of unsafe sex. Vulnerability is much more complex than the obvious and tragic cases of street children and orphans, of whom UNAIDS estimates there will be 40 million in 2010.

In February 1999 the current World AIDS Campaign with Children and Young People, *Listen, Learn, Live!* was launched by UNAIDS and the Brazilian President, Fernando Henrique Cardoso. It builds on the 1997 campaign *Children Living in a World with AIDS* and the 1998 *Force for Change: World AIDS Day Campaign with Young People*. Partners in the Campaign include Music Television International (MTV), International Save the Children Alliance, the World Association of Girl Guides and Girl Scouts, and the World Organization of the Scout Movement. The seven critical elements identified in a global strategy are:

- establishing/reviewing national policies to reduce vulnerability and ensure human rights;
- promoting genuine participation of young people in expanding national responses;
- supporting peer and youth groups to contribute to this response;
- mobilizing parents, media, religious leaders and decision-makers to influence public opinion and policy;
- improving the quality and coverage of school programmes which include HIV/AIDS in appropriate contexts;
- expanding access to youth-friendly and nonjudgmental health services; and
- ensuring care and support of orphans and young people living with HIV/AIDS.

Young people need to be equipped with the necessary knowledge, life skills and services to adopt protective behaviour. Open communication, including the use of modern marketing techniques, is a key feature of working successfully with young people.



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Programmes include the UNAIDS/UNICEF *Play Safe* Initiative which is headed by Ronaldo, the Brazilian football player. Schools are a prime site for reaching children and young people. In Kampala, Uganda, the independent radio station Capitol Radio provides a popular forum for adolescents to openly discuss sex and HIV/AIDS problems with experts. The CARICOM multi-agency Family Health and Life Education project in Latin America provides integrated health classes on sexual health, drug prevention and HIV/AIDS education.

Peer education is an effective communication strategy, particularly for vulnerable populations such as young people. Peer educators speak the same language, share the same values and are effective in reaching young people. In Lusaka, Zambia, 52 young people were trained as peer counsellors within primary health care clinics to provide support services, and link staff with young clients. The programme has enhanced mutual respect between adults and young people in the community, and helped break down the taboo on discussing sex.<sup>179</sup>

Best practice in protecting the human rights of children and reducing vulnerability to HIV has been demonstrated in several Brazilian projects. The Brazilian Centre for the Rights of Children and Adolescents in Rio de Janeiro operates in a high HIV prevalence area with street children. It provides basic assistance with matters such as obtaining a birth certificate – an important concern because lack of a birth certificate creates difficulties in enrolling for school, and adversely impacts on employment.<sup>180</sup> The Woman Life Collective in Brazil works with survivors of childhood sexual abuse to build girls' self-esteem and stop them entering into sex work or street gangs. In Recife safe houses, such as Casa de Passagen, for girls relieve them from the pressure of the street and enable them to regain feelings of security and control of their lives.<sup>181</sup>

Placing HIV/AIDS on the agenda of existing ministerial forums is a practical means of highlighting problems. The first World Conference of Ministers Responsible for Youth in Lisbon, Portugal, in August 1998 was attended by delegations from over 100 countries.

A dramatic impact was made in Australia by the National Inquiry into Homeless Children conducted by the Human Rights and Equal Opportunity Commission (HREOC) in 1989. The Inquiry commissioned studies, visited facilities, held hearings with witnesses in many locations, and received a large number of submissions. The Inquiry was able to convince governments that basic human rights were being denied to these children and that a comprehensive and urgent response was required. One finding referred to the increased risk of HIV infection because many street children were involved in prostitution, unsafe sex and injecting drug use. Governments accepted most of the Inquiry's recommendations after sustained pressure from many fronts, including the media, community groups and NGOs.<sup>182</sup>

## Religious minorities

Many minority groups who are vulnerable to HIV infection lack targeted programmes. The factors influencing vulnerability usually vary between minority populations. General programmes can fail to reach minorities because of communication barriers such as language and social norms, which can make people think that the education or prevention messages are not relevant to them.

A case study of best practice in relation to religious minorities, which also has beneficial effects for women and children, is the Family AIDS Education and Prevention through Imams project which targets the Muslim population in Uganda (16% of a total population of 20 million).<sup>183</sup> In 1992 the Islamic Medical Association started the project, which is funded by international donors,<sup>184</sup> and has trained and supervised more than 8000 religious leaders and volunteers (equal numbers of males and females), reaching over 100,000 families in 11 districts. Condoms were included as a training workshop topic in the second year of the project following dialogue with leaders about the need for education on their responsible use. Fears that discussion of condoms would promote sex outside marriage, which is against Islamic law, were eventually allayed.<sup>185</sup>

Each Imam (mosque leader) receives a bike for himself and his team of volunteers to facilitate visits, as well as the means to start an income generating-activity to support participants, like small businesses selling food. A major impact of the latter has been the empowerment of women, by increasing self-respect, financial independence and encouraging avoidance of high-risk behaviour. This facilitates the making of important decisions to protect the health of families, e.g. not looking for extramarital partners to contribute to household income, and educating children, thus maximizing their chances of employment and ability to understand HIV/AIDS messages.

This innovative project helps Imams incorporate accurate information about HIV/AIDS into their spiritual teachings. The teams of volunteers are able to make individual home visits providing education, basic counselling and motivation for behaviour change. Certain traditional practices have the potential to increase the risk of HIV transmission in some circumstances, such as male circumcision (e.g. unsterilized instruments), ablution of the dead (e.g. failure to use protective gloves when cleaning bodily orifices) and possibly polygamy. Using trusted members of the community as models for behaviour allows social norms to be considered in a personal context e.g. the responsibility not to harm others.

An allied project exists in Madarasa schools (informal weekend schools attached to mosques, where Islamic culture and behaviour is taught). An age-appropriate AIDS curriculum has been developed for classes of mixed age groups under which 20,000 Muslim children have been educated since 1995.

## Guideline 9: Changing discriminatory attitudes through education, training and the media

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.

Education programmes designed to change discriminatory attitudes are an essential complement to the reform of antidiscrimination legislation. Reducing prejudice against PLWHAs is important and practical, as it removes barriers to early diagnosis and treatment.

Harnessing existing expertise is a powerful way to change attitudes, as shown by the MTV video *Staying Alive* that was broadcast globally on World AIDS Day 1998 and targeted young people. Another effective example was the late Princess Diana of Wales who publicly made physical contact with people living with HIV/AIDS, by hugging, shaking hands or kissing them.

### *Targeted projects*

Workshops for parliamentarians have been held in Honduras, Kyrgyzstan, Mozambique and Panama to raise awareness of HIV/AIDS issues and sensitize politicians to human rights issues. These workshops recognize HIV/AIDS as an internal as well as an external issue, and have been successful in creating a climate of nondiscrimination and openness in parliaments. In Zambia the then President, the Honourable Kenneth Kaunda, publicly acknowledged that his son had died of AIDS. In Britain, a member of parliament spoke of his brother's death from AIDS. In October 1996 a member of the Japanese House of Representatives was elected on the basis of his participation, as a haemophiliac, in litigation against the government and pharmaceutical firms after he became HIV-infected through the blood supply.<sup>186</sup>

The judiciary have also been targeted in some countries – e.g. a two-day workshop on HIV/AIDS Law and Ethics was held by the Lawyers Collective, India, in Mumbai during January 1999.<sup>187</sup> The objective was to sensitize judges and create awareness of HIV/AIDS issues that might emerge in the courts. The topics covered included: discrimination; vulnerable groups; public health (testing, counselling and confidentiality); blood safety; media; and the ethics of research. Keynote speakers included judges with long-standing interest and expertise in HIV/AIDS and human rights issues, namely Justice Edwin Cameron of South Africa and Justice Michael Kirby of

Australia. On 20 April 1999 Justice Cameron publicly disclosed before the South African Judicial Service Commission that he was living with AIDS.

An Australian project targets health-care workers by systematically reviewing institutional and professional matters that may be linked with discrimination (such as universal infection control, informed consent and confidentiality). This project in two city hospitals and two rural hospitals de-emphasized antidiscrimination, but incorporated this goal into wider issues of improving service delivery and integrating recommended practices into institutional routine activities, making them ultimately more sustainable. Health-care professionals were involved in the review, thereby increasing their commitment, and identifying problems and solutions at a level deeper than that which could have been achieved using outsiders.<sup>188</sup>

### *General media campaigns*

Generic antidiscrimination campaigns that include HIV/AIDS as examples can be effective, as was demonstrated in Spain by a campaign based on generalized respect for people. The government in Australia during 1992 ran public education campaigns and 1994 called *HIV Doesn't Discriminate, People Do* and *Don't judge what I can do by what you think I can't*. The first challenged attitudes and stereotypes by pointing out that it was safe to have everyday social contact with PLWHAs. It used real people (with informed consent), rather than actors, to give sympathetic testimonials of their lives, to show that they had normal relationships as friends, relatives, work colleagues, neighbours and partners. Where people had died since the making of the prime time television advertisements, the dates of birth and death were shown. The second campaign supported the *Disability Discrimination Act 1992*. The campaign was preceded by a conceptual mapping of the underlying causes of discrimination which were found to be fears associated with contagion, drug use, sexuality and homophobia. Health-care workers were identified as setting the parameters of community understanding of the epidemic.<sup>189</sup>

Other projects supported these public education campaigns, aiming to minimize HIV-related discrimination. One project informed PLWHAs about their rights through workshops, enhancing advocacy skills, educating service providers about the needs of PLWHAs and assisting mainstream agencies and communities (e.g. in the workplace and public housing) to create and develop a supportive environment. Resources used included booklets and pamphlets on superannuation, confidentiality, civil rights and estate planning. There was a focus on the development of PLWHAs as educators. Speakers Bureaux were established to give a human face to HIV/AIDS and increase the legitimacy and impact of antidiscrimination messages. Volunteer PLWHAs were available to talk to interested groups such as schools and other institutions and were thus able to undermine stereotypes. Barriers identified by the projects included literacy, fluency in language, ethnicity, class, gender, assertiveness, other factors leading to marginalization (such as drug use), access to and availability of services, and rural

isolation.<sup>190</sup> These broad-ranging strategies revealed the complex nature of discrimination and the lack of simple solutions to address it. They highlighted the need take into account the diverse personal and social factors influencing the experience of being positive, such as the existence of other stigmatizing factors, and the priority HIV-related discrimination took in a person's life compared with other issues, such as employment and housing.<sup>191</sup>

Four quantitative tracking surveys were conducted to monitor changes in knowledge and attitudes to HIV/AIDS. They found a gradual decrease in discriminatory attitudes towards PLWHAs and vulnerable groups, particularly homosexuals, but with the exception of injecting drug users.<sup>192</sup> A complementary project during this period was the development of an HIV/AIDS Media Guide in 1995, which promotes a responsible rather than sensational approach, using appropriate rather than stigmatizing language.

#### Guideline 10:

### Development of public and private sector standards and mechanisms for implementing these standards

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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.

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Innovation is a key theme in the development of public-private sector partnerships to respond effectively to the epidemic.<sup>193</sup> An obvious area for collaboration in developing codes of conduct is the medical profession where much work has been done around the world, e.g. the South African Medical and Dental Council Guidelines on HIV/AIDS, and the British Medical Association's Statement on AIDS.

Another important area is employment. In order to guarantee rights to a safe, healthy and nondiscriminatory workplace, national policies on HIV/AIDS and employment need to be developed by tripartite bodies, i.e. government, employers and unions. A regional example is the Southern African Development Community (SADC) HIV/AIDS Employment Code of Conduct.<sup>194</sup> The fundamental principle underpinning the Code is that HIV/AIDS should be treated like other comparable life-threatening diseases. It covers issues such as discrimination, informed consent to testing, confidentiality, access to benefits, sick leave, compensation, dispute resolution, grievance

and disciplinary procedures. The Code was drafted by the AIDS Law Project and Consortium on Legal Rights and AIDS in a process that included input from trade unions, employers and government, in an intensive advocacy and lobbying campaign. In September 1997 the Code was formally endorsed by the 15 heads of government from SADC countries, who are now in the process of national implementation. Countries such as Namibia have adopted the Code, in the light of their Constitution.<sup>195</sup> It has also been adopted by a number of local councils and private companies, some of which have adapted it as their own policy document.

National level examples exist in many countries:

- The Tokyo Chamber of Commerce and Industry prepared a Handbook for members. The Auto Industry Employers Association adopted guidelines on HIV/AIDS education, privacy and nondiscrimination in 1993. The Japanese Ministry of Labour drafted guidelines in 1995 which emphasize privacy, confidentiality, and ensuring that being HIV-positive is not a cause for dismissal.<sup>196</sup>
- An AIDS in the Workplace policy and information package was developed by the Confederation of Indian Industry.<sup>197</sup>
- The Thailand Business Coalition on AIDS formed in 1994 has, among other activities, produced a Manual on HIV/AIDS in the workplace.<sup>198</sup>

A further area of possible collaboration is the media. At the 1998 African Media Congress on HIV/AIDS and Reproductive Health/Rights a Code of Ethics was drafted which covers issues such as: the need for basic understanding of HIV/AIDS issues; privacy; use of correct and nonstigmatizing terminologies; ethics and responsibility.

## Guideline 11: State monitoring and enforcement of human rights

States should ensure monitoring and enforcement mechanisms to guarantee HIV-related human rights, including those of people living with HIV/AIDS, their families and communities.

Principles relating to the establishment of national human rights institutions were resolved by the UN Commission on Human Rights in Paris in 1992. These Principles recognize the role of strong and effectively operating national infrastructures in prac-

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tical realization of human rights at country level. There are about 30 such institutions with varying structures appropriate to the national political, cultural and economic situation, but common purposes and goals around the world including, Australia, Canada, Malawi, New Zealand, Philippines, South Africa, Sri Lanka, the UK, and the USA. These institutions are best enshrined in legislation, rather than mere administrative arrangements. The common functions they perform are:

- educational and promotional activities;
- provision of advice to government on human rights issues;
- investigation, conciliation and/or resolution/arbitration of individual complaints, usually about discrimination on enumerated grounds such as disability, gender and race, against public (and sometimes private) agencies; and
- monitoring compliance domestic legislation with international human rights treaties and norms.

Most legislations creating effective national institutions have the following features, based on the Paris Principles:<sup>199</sup>

- independence from other organs of government;
- defined jurisdiction, such as being based on a constitutional charter of rights or international human rights instruments;
- accessibility – physical (e.g. decentralized) and visible, in terms of awareness of the institution's existence among potential clients from vulnerable groups;
- cooperation with NGOs and community groups, other national institutions and intergovernmental organizations, such as the UN; and
- accountability – direct reporting obligations to Parliament with details of frequency, issues to be covered and procedure for submitting and examining reports.

UNAIDS, the Office of the High Commissioner for Human Rights and UNDP have commenced two-year projects in Uganda and India to assist national human rights institutions in those countries to integrate HIV/AIDS issues. The expected outcome is to increase compliance with international human rights treaty obligations at national level and to build capacity to report accurately on such compliance to the UN treaty monitoring bodies.

The Ugandan Human Rights Commission was established in 1997 under sections 51-58 of the 1995 Constitution. The President, with the approval of Parliament, appoints the Chairperson and three other members. The Commission has a broad jurisdiction

to deal with any human rights issue. Although it is empowered to investigate in response to complaints and on its own initiative, the Commission has tended to investigate alleged violations reported in the media. It works collaboratively with NGOs in areas such as monitoring compliance with international human rights obligations and performing civil education. It also works collaboratively with the Judicial Commission, the Law Society, trade unions and other groups. The first inquiry into systemic violations of human rights has commenced in relation to street children.

The National Human Rights Commission of India was established in 1993. As well as a Chairperson and four other members, there are three ex officio members – the Chairpersons of the National Commissions for Minorities, Scheduled Castes and Tribes, and Women. Its mandate includes civil, political, economic, social and cultural rights. It too can investigate individual complaints or on its own initiative. One major area of systematic human rights violation that the Commission has dealt with is custodial violence. Other significant areas of work include women, children and people with disabilities. The Commission chairs the International Coordinating Committee of National Institutions, which was established at the 1993 World Conference on Human Rights.

Another method for promoting observance of human rights at national level has been the preparation by governments of National Action Plans on Human Rights that describe current policies, analyse future challenges and propose national action. Such plans have been recommended at the Beijing and Vienna Conferences and are promoted by the UN High Commissioner for Human Rights.

## Guideline 12: International cooperation

States should cooperate through all relevant programmes and agencies of the United Nations system, including UNAIDS, to share knowledge and experience concerning HIV-related human rights issues, and should ensure effective mechanisms to protect human rights in the context of HIV/AIDS at the international level.

UN Theme Groups on HIV/AIDS at country level provide a structure to enable agencies to coordinate and jointly plan action and support for national AIDS programmes. They are responsible for policy making, advocacy, mobilizing resources, providing financial and technical support, collecting, analysing and sharing information. UN agencies can assist in attaining commitment from the highest levels of national government in order to achieve immediate and significant action. In Mozambique, meetings of the UN Theme Group with the President and Prime Minister led to the inclusion of



HIV/AIDS human rights issues into new labour legislation and mitigation actions in new investment planning.<sup>200</sup> Regular meetings between politicians and UN Theme Groups in other countries have also been important, such as meetings with the Deputy Prime Minister in Viet Nam and the Vice-Premier in the Dominican Republic.<sup>201</sup>

An innovative suggestion was made, in the interests of globalization and burden sharing in the international community, at the UNAIDS and IPU Working Group meeting that considered a draft of this Handbook in February 1999. It recommended that development assistance programmes should provide short-term scholarships for lawyers to be trained and sensitized to HIV/AIDS and human rights issues. In 1995 UNDP conducted training workshops in Beijing (China), Nadi (Fiji), and Colombo (Sri Lanka) on HIV Law and Law Reform. They were designed as capacity-building exercises that could have a catalytic effect at national level.<sup>202</sup> UNAIDS and the Office of the High Commissioner for Human Rights are already working on integrating HIV/AIDS issues into general human rights training and technical assistance projects.

#### **International compliance monitoring mechanisms**

It is well recognized that there is a need to improve human rights monitoring mechanisms at national and international levels. UN agencies, national governments, international and national NGOs all have a role to play in this area. The six UN treaty-monitoring bodies established to monitor compliance with the main human rights treaties need to be better utilized to ensure appropriate rights-based responses to the epidemic by States Parties. Under these existing accountability mechanisms, governments that are signatories to the treaties are required to submit periodic reports on their progress in implementing its provisions. NGOs are also able to submit shadow reports at special sessions of the Committees before these Committees dialogue with the government.

A study of these Concluding Observations of four Committees (covering women, children, economic, social and cultural rights and civil and political rights) revealed that HIV/AIDS was mentioned in 24% of the total 211 reports produced between 1993 and 1998. Of these, 43% consisted of comments, 22% of questions and 35% of directive recommendations. The most common recommendations were the need to: strengthen or adopt prevention programmes, i.e. information, education and services; adopt measures for PLWHAs, mainly to address discrimination, or; address sex tourism, involve women political leaders in information and education campaigns, or gather data on incidence or its impact on vulnerable populations.<sup>203</sup>

Work has commenced on improving the depth of consideration of HIV/AIDS issues by the treaty bodies.

- In December 1996 a meeting in Glen Cove, New York, was jointly convened by UNFPA, United Nations Division for the Advancement of Women (UNDAW) and the UN High Commissioner for Human Rights to explore

human rights approaches to women's health, focusing on reproductive and sexual health and rights.

- UNFPA and UNAIDS addressed the annual meeting of the treaty bodies chairpersons in Geneva in September 1997. UNAIDS encouraged the treaty bodies to deepen their understanding of the relationship between human rights and HIV/AIDS, to integrate these issues in their work, particularly in drafting Reporting Guidelines, General Comments and Recommendations, and country-specific Concluding Observations. Cooperation and technical assistance was offered by UNAIDS and NGOs (with ICASO, the International Council of AIDS Service Organizations, as a focal point) to provide the treaty bodies with HIV-related information on national situations, and input during the report-back procedure.
- UNAIDS has produced a *Guide to the UN Human Rights Machinery* for AIDS service organizations, PLWHAs and others working in the area of HIV/AIDS and human rights. The UNAIDS Guide is designed to assist organizations in understanding the workings of the UN machinery to enable them to participate in it, by documenting practices and advocating for and with PLWHAs in respect of their human rights.
- In October 1998 UNAIDS coordinated the general theme day for the Committee on the Rights of the Child entitled *Children Living in a World with AIDS*.

As governments are the responsible States Parties for complying with international human rights norms at national level, the role of existing mechanisms of accountability to monitor their performance needs to be fully respected by them. Improving the quality of country reports submitted to the UN human rights treaty bodies in respect of HIV/AIDS issues requires effort by at least three sectors: the government preparing the report; national and international NGOs; and the treaty bodies examining it. All these parties also need to follow up on implementation of recommendations made in regard to the report.

The UN *Manual on Human Rights Reporting*<sup>204</sup> assists countries in providing timely and comprehensive information on measures taken to fulfil substantive treaty obligations and facilitates compliance with the reporting process. The Manual is based on experiences in regional training courses run by the UN for national officials responsible for preparing and submitting periodic reports to the treaty bodies. It recognizes that reporting “is at the heart of the international supervision of the domestic implementation of treaty obligations”.

The reporting process should be seen as an opportunity for constructive dialogue between the State Party and the independent international group of experts, rather than a burden imposed for the sake of undermining national sovereignty. Investment

in resources to produce a quality report that is part of a continuing process of realizing human rights at national level can assist in governments' accountability to its citizens.<sup>205</sup> UNAIDS is committed to assisting countries in addressing HIV/AIDS issues in their reports, particularly by use of the Theme Groups supported by Country Programme Advisers and InterCountry Technical Teams. UNAIDS plans to develop model reports that adequately address HIV/AIDS in a human rights framework relating to women and children.

## NGO mobilization

ICASO developed a Plan on Human Rights, Social Equity and HIV/AIDS in June 1998 following an inter-regional consultation in March 1998. The Plan uses the International Guidelines as a platform for the development of educational and advocacy activities and initiatives. Several regions of ICASO have already developed specific workplans showing how human rights issues will be incorporated into their work. A major difficulty has been attempting to improve linkages between HIV/AIDS Organizations and human rights NGOs. Several workshops and meetings at the 12th World AIDS Conference in Geneva in June-July 1998 were focused on this issue of improving links between the human rights and HIV/AIDS communities.

## Religious leaders

The need to strengthen links with religious leaders in the expanded response to HIV/AIDS has been a challenge worth pursuing for many reasons. Most religious organizations have been involved in treatment and care issues since the early days of the pandemic. The deeply embedded connection that religious leaders have with the community also makes them a great source and support for HIV/AIDS and human rights education and information activities. Opposition to sexually explicit educational materials and promotion of condoms has been an actual and potential problem requiring forums for constructive dialogue between religious and public health groups in many countries.<sup>206</sup> The successful Imams project conducted in the Islamic community of Uganda has already been described (page 97). Another successful project has been undertaken with the majority Christian communities in Kenya by MAP International, a nonprofit relief and development NGO, with funding from AIDS Control and Prevention (AIDSCAP) Project.<sup>207</sup>

A significant breakthrough was the holding of the first International Conference on Religion and AIDS in Dakar, Senegal, in 1997 which made a Declaration of People Living with HIV/AIDS. A recent development in this area has been the signing of a Memorandum of Understanding between UNAIDS and Caritas Internationalis (CI), one of the world's largest NGO networks. CI is an international Catholic confederation of 146 members with a broad national-level network of charities involved in relief, development and social work in 194 countries and territories. Under the

Memorandum of Understanding both parties agree to work together where possible to: promote HIV/AIDS awareness; address wider development issues highlighted by the pandemic; and promote advocacy work.<sup>208</sup> Cooperation will further assist with issues such as access to care and policy development, as well as obtaining accurate information and addressing the impact of the epidemic particularly on vulnerable members of society.

# IV. CONCLUSION

The aim of this Handbook has been to assist legislators to integrate HIV/AIDS and human rights into their parliamentary mandates by providing information on the links between these two areas in a practical way. This should enable implementation of the IPU Resolution and the International Guidelines at national level, where laws and budgets are debated and drafted. The role of the IPU in this partnership with UNAIDS has been critical, and will continue to be so in promoting the use of this Handbook.

Without a rights-based response the impact of and vulnerability to infection will increase, and the community's ability to respond will be hampered. As often highlighted by the late Jonathan Mann, the protection of the uninfected majority is inextricably bound to upholding the rights of people living with HIV/AIDS.

The existing human rights framework contains binding and international agreed norms that are comprehensive and coherent, as well as institutions to promote accountability. It provides a solid and powerful basis for measuring whether responses have been effective in reducing the vulnerability of disempowered and stigmatized populations. For example, it can measure whether these groups are being reached by targeted prevention information and education, and the impact on those already infected or affected.

The controversial and complex issues raised by HIV/AIDS may have differing relevance in diverse countries. National and community consultative processes are necessary to achieve a workable consensus, in order to assess priority areas requiring action. Issues of public health should not be clouded with morality.

Lacks of political commitment, denial and disengagement with affected communities have been features of inadequate responses to the epidemic in some countries. Without the intensive and long-term involvement of parliamentarians who can make a difference the epidemic will continue to grow unabated. Already the number of people infected with HIV has exceeded 33 million – the question is how many more lives are needed for AIDS to be treated urgently and efficiently in expanded responses by governments?

# ANNEX A

## Medical facts

AIDS is the end stage of infection with the human immunodeficiency virus (HIV-1 and, less commonly, HIV-2). The virus was first isolated in 1983 and since 1985 HIV tests have been available. These generally test for antibodies to the virus, rather than the virus itself. The virus cannot be transmitted by casual contact. The virus is transmitted through:

- sexual intercourse;
- re-use of contaminated needles and syringes, whether through medical procedures or injecting drug use;
- breast-feeding from mother to child or perinatally; and
- transfusion of contaminated blood or blood products.

Peaks of infectivity are thought to coincide with periods of high viral loads, during the initial acute stage of infection and the very end of the asymptomatic period.

Worldwide, sexual transmission accounts for about 75% of cases, and three-quarters of those are through heterosexual sex and one quarter through sex between men. The main barrier method to prevent transmission of HIV during penetrative sex is the traditional “male” condom, and the recently developed “female” condom. Work is still continuing on the development of an effective microbicide for vaginal and/or rectal administration to decrease the risk of HIV and STD transmission.<sup>209</sup> It is critically important to develop prevention methods that are controlled by the receptive sexual partner to overcome barriers of negotiating safer sex where there is an imbalance of power. The presence of untreated symptomatic sexually transmitted diseases (e.g. herpes and syphilis) is a significant co-factor, as genital ulcers are thought to enhance the risk of transmission per exposure. An estimated 340 million new cases of infection with STDs occurred around the world in 1995 according to WHO estimates.<sup>210</sup>

After transmission, which is accompanied by a week or two of flu-like symptoms (the primary or acute stage), there is a “window period” of about 6 to 12 weeks when antibodies to the virus have not yet been produced. HIV infection is asymptomatic for 10 years on average, although this period may be as short as five to seven years in some developing countries because of generally poorer health and nutritional status, as well as lack of treatment for opportunistic infections like tuberculosis (which causes around 30% of all AIDS deaths).<sup>211</sup> The disease then destroys the immune system in the vast majority of cases, leaving people vulnerable to opportunistic diseases (such as pneumonia and AIDS-associated cancers) which are usually fatal within 6 to 24 months, depending on availability of treatment. Although antiretroviral combination

therapy<sup>212</sup> has had promising results in industrialized countries, it is far from affordable in most of the developing world at present.<sup>213</sup>

## Recent initiatives in vaccine development and access to treatment

The IPU Windhoek Resolution identified major concerns with delays in the development of a vaccine, and the gap between access to treatments between developed and developing countries. This section describes recent initiatives taken by UNAIDS and others to begin addressing these issues.

### *Vaccine development*

In developing countries, where 95% of HIV/AIDS cases have occurred, antiretroviral treatment is too expensive to be widely implemented, although some improvements in accessibility have been made (see below). The development of a vaccine to prevent acquisition of HIV, or progression of disease in those already infected, is the most realistic means to stem the pandemic in the long term (with information, education, prevention and care programmes continuing in the meantime).

The development of a safe, effective and affordable vaccine is one of five global UNAIDS objectives, and several of the programme's activities are directed towards achieving this urgent goal. UNAIDS advocates for the rapid development of vaccines appropriate for developing countries, and promotes their clinical evaluation, with the highest scientific and ethical standards. UNAIDS provides independent and authoritative scientific and ethical advice to countries considering the conduct of human trials.

As part of its normative role, UNAIDS has recently developed, through a nine-month process of broad consultation and consensus building involving 200 people from over 30 countries, ethical guidelines for the conduct of these trials which complement the 1993 CIOMS<sup>214</sup> and WHO International Ethical Guidelines for Biomedical Research Involving Human Subjects. Dr Peter Piot, Executive Director of UNAIDS, said that the guidelines heralded a new era of cooperation and capacity-building between countries:

**“We have come to a new era in which paternalism and resource imbalance is being replaced by empowerment in decision-making and equality in partnership between sponsors and hosts of scientific research.”**

UNAIDS also assists selected developing countries to build their capacity to conduct vaccine research activities. UNAIDS-sponsored National AIDS Vaccine Plans are being implemented in Brazil, Thailand and Uganda, and other countries are initiating the same process. These plans provide guidance on policy, procedures and specific recommendations for vaccine-related research. In addition to several Phase I/II vaccine trials that have been conducted in the USA and Europe, several small-scale

(Phase I/II) HIV vaccine trials have also been conducted in Brazil and Thailand, and will start shortly in Uganda. The first large-scale Phase III efficacy trial has started in Thailand, and is expected to start soon in the USA. All these activities are done in close collaboration and partnership with national authorities and scientists in developing countries, international AIDS-research bodies, the pharmaceutical industry, and NGOs such as the International AIDS Vaccine Initiative (IAVI).

At the Denver Summit of G8 nations there was agreement to act urgently in response to the challenge by the US President to develop a vaccine within a decade.<sup>215</sup> Similarly the Birmingham Summit of G8 nations pledged international effort to reduce the pandemic through vaccine development, preventative programmes, appropriate therapy and support for UNAIDS. IAVI has recently launched a campaign for the creation of a Global HIV Vaccine Purchase Fund and the World Bank is currently exploring different potential models.<sup>216</sup>

### *Drug access initiatives*

UNAIDS launched the pilot phase of the HIV Drug Access Initiative in November 1997 in four developing countries – Chile, Côte d'Ivoire, Uganda, and Viet Nam. Distribution in the first two countries was announced at the 12th World AIDS Conference on 30 June 1998 where the conference theme was *Bridging the Gap*. The Initiative is a public-private collaborative effort whereby the pilot countries will adapt their health-care infrastructures and drug-distribution systems to the HIV context to ensure effective use and distribution of treatment drugs, and participating pharmaceutical and diagnostic companies will subsidize purchase of the drugs. Although the pilot is limited to two years, ongoing evaluation will monitor its efficiency, the improvement in overall health-care delivery, the increased number of people receiving drugs, and the impact on HIV/AIDS illnesses and death rates. Once information is obtained about ways to address obstacles to ensure effective distribution of HIV/AIDS-related drugs in developing countries, countries will be in a better position to mobilize resources for treatment. The intention is that the collective experience will provide the basis for an action plan to widen access to HIV-related drugs in the developing world.

In 1997 550,000 infants acquired HIV infection perinatally or through breast-feeding. The rate of transmission is about 25%, but the ACTG 076 clinical trial of 1994 found that, where zidovudine was given to HIV-positive women in developed countries, the risk of transmission drops to about 8%.<sup>217</sup> This regimen is costly as it requires several months of treatment for the mother and infant, including intravenous doses during labour. In February 1998 the US Centers for Disease Control and Prevention (CDC) announced that a short oral course of zidovudine given late in pregnancy and during delivery reduced the rate of HIV transmission to infants of infected mothers by half and is safe for use in the developing world. The study was conducted in Thailand from 1996 and was one of two CDC collaborative perinatal HIV prevention studies. The



other study in Abidjan (Côte d'Ivoire) is continuing, but the placebo-control arm is no longer necessary and all women in the study are now offered the short-course zidovudine regimen.

At the 12th International AIDS Conference UNAIDS and two of its Cosponsors, UNICEF and WHO, announced their support for pilot projects to reduce mother-to-child transmission in 11 low-income countries in Africa, Asia and Latin America where women have high rates of HIV infection. The initiative will aim to provide voluntary and confidential counselling and testing for pregnant women, antiretroviral drugs for those who learn that they are infected, better birth care, counselling about choice and provision of safe infant feeding methods. It will also provide support for HIV-positive mothers who decide not to breastfeed, which may result in stigmatization (because of the visibility of such an act in developing countries, inferences can be drawn about the mother's HIV status). Glaxo Wellcome will provide the initial supply of zidovudine in the pilot projects that will seek to support approximately 30,000 HIV-infected women in about 30 different sites over the next 12-18 months. As the initiative expands, the company will offer preferential pricing to the UN agency partners and others for use in developing countries.<sup>218</sup>

## ANNEX B

### **Resolution unanimously adopted by the 99th Inter-Parliamentary Union Conference (Windhoek, 10 April 1998)**

#### **ACTION TO COMBAT HIV/AIDS IN VIEW OF ITS DEVASTATING HUMAN, ECONOMIC AND SOCIAL IMPACT**

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INTER-PARLIAMENTARY UNION  
PLACE DU PETIT-SACONNEX  
1211 GENEVA 19, SWITZERLAND

The 99th Inter-Parliamentary Conference,

*Recalling* the previous resolutions of the Inter-Parliamentary Union concerning HIV/AIDS, particularly that of the 87th Conference (Yaoundé, April 1992),

*Concerned* by the speed at which the HIV/AIDS epidemic is spreading throughout the world, particularly among women and children,

*Noting* the growing awareness of the seriousness of AIDS as a disease to which anyone can be exposed, regardless of ethnic origin, age group, geographical situation and level of economic or social well-being,

*Emphasising* the harmful impact of AIDS on society, economies and development, which jeopardises world economic growth and threatens political and social stability,

*Acknowledging* that balancing the rights and responsibilities of a broad spectrum of people is a formidable but necessary legislative task of parliaments,

*Mindful* that women and children as well as groups which are underprivileged socially and economically or in terms of the law, and those with no legal status, are less aware and therefore more vulnerable to the risks of infection from HIV/AIDS because they may be barred from full access to education, health care, social services and other means of prevention and control, and *acknowledging* that they suffer disproportionately from the economic and social consequences of the HIV/AIDS epidemic,

*Convinced* that both authorities and society as a whole must spare no effort to prevent and contain the spread of HIV/AIDS and ease the impact of this pandemic on respect for human rights and civil liberties,

*Deeply concerned* by the ever-widening gap between developed and developing countries in terms of possibilities for screening, identifying, monitoring, treating and ensuring the social integration of people with AIDS, which is the more serious as the great majority of those affected live in developing countries,

*Reminding* States of the commitments they have undertaken to promote and encourage respect for human rights in instruments such as the Universal Declaration of Human Rights, the United Nations Charter, the International Covenant on Economic, Social and Cultural Rights, the International Covenant on Civil and Political Rights, the International Convention on the Elimination of All Forms of Racial Discrimination, the Convention on the Elimination of All Forms of Discrimination against Women, the Convention Against Torture and other Cruel, Inhuman or Degrading Treatment or Punishment and the Convention on the Rights of the Child, as well as the conventions of the International Labour Organisation, the Vienna Declaration and Programme of Action, the Beijing Declaration, resolutions 1994/24 and 1997/52 of the UN Economic and Social Council, the Cairo Programme of Action, the Declaration of the Paris Summit of 1 December 1994, the G-7 Development Ministers, Joint Declaration of 1 December 1997 and the resolution of the ASEAN Inter-Parliamentary Organisation (AIPO) on the Maintenance of Health and Prevention of the Spread of HIV/AIDS adopted at the 18 General Assembly of AIPO in Bali, Indonesia, in September 1997,

*Recognising* that HIV/AIDS spreads beyond borders and must accordingly be fought through joint action by the international community and international organisations, especially UNAIDS and its co-sponsors (UNICEF, UNDP, UNFPA, UNESCO, WHO, World Bank),

*Reaffirming* the principles set out in the World AIDS Strategy adopted by WHO and endorsed by the UN General Assembly, the main goals of which are as follows:

- (a) Preventing HIV infection;
- (b) Reducing the effects of infection on individuals and society;
- (c) Mobilising and combining national and international efforts to combat AIDS,

*Convinced* of the need to act on a global scale to ensure that despite overstretched public budgets, no effort is spared to reduce the number of new cases of HIV/AIDS,

*Recalling* that adopting legislation on the rights and obligations of persons is one of the primary duties of parliaments,

1. *Urges* parliamentarians to evaluate properly the growing impact of the HIV/AIDS epidemic on world economic development and on social and political stability, and to become aware of the resulting daily violations of the inalienable rights of individuals;
2. *Urges* governments and NGOs to adopt a long-term, timely, coherent and integrated AIDS prevention policy with public information and education programmes which are specifically tailored to the needs of the various target groups and take account of cultural and religious sensitivities, and thus provide universally accessible information about the various routes of HIV transmission and highlight ways of avoiding or at least reducing the risk of infection;
3. *Calls on* the more prosperous countries, in accordance with the principle of inter-

- national solidarity, to help less developed countries, to take on appropriate additional burdens and to offer financial assistance and technical and social support;
4. *Also calls on* governments, scientific organisations and the pharmaceutical industry to co-operate in funding and reinforcing AIDS vaccine research, as proposed by the International AIDS Vaccine Initiative, and *invites* the pharmaceutical industry in particular to invest massively in such research;
  5. *Calls for* negotiations between wealthy and poorer countries to devise ways of enabling every person living with HIV/AIDS to benefit from the best treatments possible in light of current medical knowledge;
  6. *Calls on* developed countries, as well as international organisations and financial institutions, to earmark part of their development assistance to support national AIDS programmes in the developing world;
  7. *Urges* governments to ensure the protection of human rights by putting into practice the guidelines adopted by the Second International Consultation on HIV/AIDS and Human Rights (September 1996). Special consideration should be given to the following:
    - (a) Review and reform existing public health laws so as to ensure that they address the issues raised by HIV/AIDS and comply with international human rights obligations (protection of privacy, confidentiality, liberty and security of the person), and that the provisions applicable to other transmissible diseases are not implemented in an inappropriate manner;
    - (b) Review and reform penal legislation and prison systems so as to ensure that they comply with international obligations for the protection of human rights, especially as regards HIV/AIDS;
    - (c) Adopt legislation ensuring that the human rights of persons infected or affected by HIV/AIDS are respected, banning all forms of discrimination against them, and establishing their right to education, work, housing and social services;
    - (d) Ensure respect for privacy, confidentiality and ethics in scientific research on human beings (informed consent, education and respect of subjects);
    - (e) See to it that public institutions and the private sector establish rules concerning HIV/AIDS which translate human rights principles into codes of professional responsibility and practice, and introduce monitoring mechanisms to ensure that they are properly applied;
  8. *Calls on* parliamentarians to encourage the involvement of all sectors of society by promoting inter-agency and multisectoral co-operation, including public-private sector partnerships as an effective means to respond to the pandemic;
  9. *Urges* parliamentarians to intensify their legislative, budgetary and oversight functions in all areas of activity relevant to HIV/AIDS prevention and control;

10. *Requests* UNAIDS, in co-operation with the IPU Secretariat, to consult IPU member parliaments in finalising the draft Handbook on HIV/AIDS, law and human rights, and to disseminate it as a reference tool for the establishment of legal standards, with progress to be reported at the next IPU Conference in Moscow;
11. *Urges* legislators to ensure that HIV/AIDS is addressed at all times through a partnership approach which involves the widest possible range of concerned stakeholders, including people living with AIDS, as well as the community, in decision-making processes and which provides for the sharing and dissemination of all relevant information on policies and medical and social issues;
12. *Calls on* governments to remove possible routes of transmission within health services, by using only blood and blood products which are guaranteed free of infection, utilising disposable hypodermic needles and ensuring strict compliance with all other hygiene regulations, including establishing needle and syringe exchange programmes, and *urges* the developed countries to provide material and technical support to the developing countries in this respect;
13. *Calls for* the establishment, in IPU member parliaments, of non-partisan parliamentary groups on HIV/AIDS to ensure ongoing dialogue, briefings and debate as well as training activities in order to deepen the understanding of the pandemic and to promote a consensus on national AIDS policy.

# ANNEX C

## International Guidelines on HIV/AIDS and Human Rights

### (A) Institutional responsibilities and processes

#### Guideline 1: National framework

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States should establish an effective national framework for their response to HIV/AIDS which ensures a coordinated, participatory, transparent and accountable approach, integrating HIV/AIDS policy and programme responsibilities, across all branches of Government.

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Depending upon existing institutions, the level of the epidemic and institutional cultures, as well as the need to avoid overlapping of responsibilities, the following responses should be considered:

- (a) Formation of an interministerial committee to ensure integrated development and high-level coordination of individual ministerial national action plans and to monitor and implement the further HIV/AIDS strategies, as set out below. In federal systems, an intergovernmental committee should also be established with provincial/state, as well as national representation. Each ministry should ensure that HIV/AIDS and human rights are integrated into all its relevant plans and activities, including:
- education
  - law and justice, including police and corrective services
  - science and research
  - employment and public service
  - welfare, social security and housing
  - immigration, indigenous populations, foreign affairs and development cooperation

- health
  - treasury and finance
  - defence, including armed services
- (b) Ensuring that an informed and ongoing forum exists for briefing, policy discussion and law reform to deepen the level of understanding of the epidemic, in which all political viewpoints can participate at national and subnational levels, e.g. by establishing parliamentary or legislative committees with representation from major and minor political parties.
- (c) Formation or strengthening of advisory bodies to advise Government on legal and ethical issues, such as a legal and ethical subcommittee of the interministerial committee. Representation should consist of professional (public health, legal and educational, scientific, biomedical and social), religious and community groups, employers' and workers' organizations, NGOs and ASOs, nominees/experts and people living with HIV/AIDS.
- (d) Sensitization of the judicial branch of Government, in ways consistent with judicial independence, on the legal, ethical and human rights issues related to HIV/AIDS, including through judicial education and the development of judicial materials.
- (e) Ongoing interaction of government branches with United Nations Theme Groups on HIV/AIDS and other concerned international and bilateral actors to ensure that governmental responses to the HIV/AIDS epidemic will continue to make the best use of assistance available from the international community. Such interaction should, *inter alia*, reinforce cooperation and assistance to areas related to HIV/AIDS and human rights.

## Guideline 2: Supporting community partnership

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

- (a) Community representation should comprise PLWHAs, CBOs, ASOs, human rights NGOs and representatives of vulnerable groups. Formal and regular mechanisms should be established to facilitate ongoing dialogue with and input from such community representatives into HIV-related government policies and programmes. This could be established through regular reporting by community representatives to the various government, parliamentary and judicial branches described in Guideline 1, joint workshops with community representatives on policy, planning and evaluation of State responses and through mechanisms for receiving written submissions from the community.
  
- (b) Sufficient government funding should be allocated in order to support, sustain and enhance community organizations in areas of core support, capacity-building and implementation of activities, including in areas concerning HIV-related ethics, human rights and law. Such activities might involve training seminars, workshops, networking, developing promotional and educational materials, advising clients of their human and legal rights, referring clients to relevant grievance bodies, collecting data on human rights issues and human rights advocacy.



## (B) Law review, reform and support services

### Guideline 3: Public health legislation

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

Public health legislation should contain the following components:

- (a) Public health law should fund and empower public health authorities to provide a comprehensive range of services for the prevention and treatment of HIV/AIDS, including relevant information and education, access to voluntary testing and counselling, STD and sexual and reproductive health services for men and women, condoms and drug treatment, services and clean injection materials, as well as adequate treatment for HIV/AIDS-related illnesses, including pain prophylaxis.
- (b) Apart from surveillance testing and other unlinked testing done for epidemiological purposes, public health legislation should ensure that HIV testing of individuals should only be performed with the specific informed consent of that individual. Exceptions to voluntary testing would need specific judicial authorization, granted only after due evaluation of the important privacy and liberty considerations involved.
- (c) In view of the serious nature of HIV testing and in order to maximize prevention and care, public health legislation should ensure, whenever possible, that pre- and post-test counselling is provided in all cases. With the introduction of home-testing, States should ensure quality control, maximize counselling and referral services for those who use such tests and establish legal and support services for those who are the victims of misuse of such tests by others.
- (d) Public health legislation should ensure that people are not subjected to coercive measures such as isolation, detention or quarantine on the basis of their HIV status. Where the liberty of persons living with HIV is restricted due to their illegal behaviour, due process protections (e.g. notice, rights of review/appeal, fixed rather than indeterminate periods of orders and rights of representation) should be guaranteed.

- (e) Public health legislation should ensure that HIV and AIDS cases reported to public health authorities for epidemiological purposes are subject to strict rules of data protection and confidentiality.
- (f) Public health legislation should ensure that information related to the HIV status of an individual is 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.
- (g) Public health legislation should authorize, but not require, that health-care professionals decide, on the basis of each individual case and ethical considerations, to inform their patients' sexual partners of the HIV status of their patient. Such a decision should only be made in accordance with the following criteria:
- the HIV-positive person in question has been thoroughly counselled
  - counselling of the HIV-positive person has failed to achieve appropriate behavioural changes
  - the HIV-positive person has refused to notify, or consent to the notification of his/her partner(s)
  - a real risk of HIV transmission to the partner(s) exists
  - the HIV-positive person is given reasonable advance notice
  - the identity of the HIV-positive person is concealed from the partner(s), if this is practically possible
  - follow-up is provided to ensure support to those involved, as necessary
- (h) Public health legislation should ensure that the blood/tissue/organ supply is free of HIV and other blood-borne pathogens.
- (i) Public health law should require the implementation of universal infection control precautions in health-care and other setting involving exposure to blood and other bodily fluids; persons working in these settings must be provided with the appropriate equipment and training to implement such precautions.
- (j) Public health legislation should require that health-care workers undergo a minimum of ethics and/or human rights training in order to be licensed to practice and should encourage professional societies of health-care workers to develop and enforce codes of conduct based on human rights and ethics, including HIV-related issues such as confidentiality and the duty to provide treatment.

## Guideline 4: Criminal laws and correctional systems

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

- (a) Criminal and/or public health legislation should not include specific offences against the deliberate and intentional transmission of HIV but rather should apply general criminal offences to these exceptional cases. Such application should ensure that the elements of foreseeability, intent, causality and consent are clearly and legally established to support a guilty verdict and/or harsher penalties.
- (b) Criminal law prohibiting sexual acts (including adultery, sodomy, fornication and commercial sexual encounters) between consenting adults in private should be reviewed, with the aim of repeal. In any event, they should not be allowed to impede provision of HIV/AIDS prevention and care services.
- (c) With regard to adult sex work that involves no victimization, criminal law should be reviewed with the aim to decriminalize, then legally regulate 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/AIDS prevention and care services to sex workers and their clients. Criminal law should ensure that children and adult sex workers who have been trafficked or otherwise coerced into sex work are protected from participation in the sex industry and are not prosecuted for such participation but rather are removed from sex work and provided with medical and psychosocial support services, including those related to HIV.
- (d) Criminal law should not be an impediment to measures taken by States to reduce the risk of HIV transmission among injecting drug users and to provide HIV-related care and treatment for injecting drug users. Criminal law should be reviewed to consider:
  - The authorization or legalization and promotion of needle and syringe exchange programmes;
  - The repeal of laws criminalizing the possession, distribution and dispensing of needles and syringes.

- (e) Prison authorities should take all necessary measures, including adequate staffing, effective surveillance and appropriate disciplinary measures, to protect prisoners from rape, sexual violence and coercion. Prison authorities should also provide prisoners (and prison staff, as appropriate), with access to HIV-related prevention information, education, voluntary testing and counselling, means of prevention (condoms, bleach and clean injection equipment), treatment and care and voluntary participation in HIV-related clinical trials, as well as should ensure confidentiality, and should prohibit mandatory testing, segregation and denial of access to prison facilities, privileges and release programmes for HIV positive prisoners. Compassionate early release of prisoners living with AIDS should be considered.

## Guideline 5: Antidiscrimination and protective laws

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States should enact or strengthen antidiscrimination 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.

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- (a) General antidiscrimination laws should be enacted or revised to cover people living with asymptomatic HIV infection, people living with AIDS and those merely suspected of HIV or AIDS. Such laws should also protect groups made more vulnerable to HIV/AIDS due to the discrimination they face. Disability laws should also be enacted or revised to include HIV/AIDS in their definition of disability. Such legislation should include the following:
- The areas covered should be as broad as possible, including health care, social security, welfare benefits, employment, education, sport, accommodation, clubs, trade unions, qualifying bodies, access to transport and other services;
  - Direct and indirect discrimination should be covered, as should cases where HIV/AIDS is only one of several reasons for a discriminatory act, and prohibiting HIV/AIDS vilification should also be considered;
  - Independent, speedy and effective legal and/or administrative procedures for seeking redress, containing such features as fast-tracking for cases where the complainant is terminally ill, investigatory powers to address systemic cases

of discrimination in policies and procedures, ability to bring cases under pseudonym and representative complaints, including the possibility of public interest organizations bringing cases on behalf of people living with HIV/AIDS;

- Exemptions for superannuation and life insurance should only relate to reasonable actuarial data, so that HIV/AIDS is not treated differently from analogous medical conditions.
- (b) Traditional and customary laws which affect the status and treatment of various groups of society should be reviewed in the light of antidiscrimination laws. If necessary, these should be reformed to promote and protect human rights, so that legal remedies are made available, if such laws are misused, and information, education and community mobilization campaigns are conducted to change these laws and attitudes associated with them.
- (c) General confidentiality and privacy laws should be enacted. HIV-related information on individuals should be included within definitions of personal/medical data subject to protection and should prohibit the unauthorized use and/or publication of HIV-related information on individuals. Privacy legislation should enable an individual to see his or her own records and to request amendments to ensure that such information is accurate, relevant, complete and up-to-date. An independent agency should be established to redress breaches of confidentiality. Provision should be made for professional bodies to discipline cases of breaches of confidentiality as professional misconduct under codes of conduct discussed below. Unreasonable invasion of privacy by the media could also be included as a component of professional codes governing journalists. People living with HIV/AIDS should be authorized to demand that their identity and privacy are protected in legal proceedings in which information on these matters will be raised.
- (d) Laws, regulations and collective agreements should be enacted or reached so as to guarantee the following workplace rights:
- a national policy on HIV/AIDS and the workplace agreed upon in a tripartite body
  - freedom from HIV screening for employment, promotion, training or benefits
  - confidentiality regarding all medical information, including HIV/AIDS status
  - employment security for workers living with HIV until they are no longer able to work, including reasonable alternative working arrangements
  - defined safe practices for first aid and adequately equipped first-aid kits
  - protection for social security and other benefits for workers living with HIV, including life insurance, pension, health insurance, termination and death benefits

- adequate health care accessible in or near the workplace
  - adequate supplies of condoms available free to workers at the workplace
  - workers' participation in decision-making on workplace issues related to HIV/AIDS
  - access to information and education programmes on HIV/AIDS, as well as to relevant counselling and appropriate referral
  - protection from stigmatization and discrimination by colleagues, unions, employers and clients
  - appropriate inclusion in workers' compensation legislation of the occupational transmission of HIV (e.g. needle-stick injuries), addressing such matters as the long latency period of infection, testing, counselling and confidentiality.
- (e) Protective laws governing the legal and ethical protection of human participation in research, including HIV-related research, should be enacted or strengthened in relation to:
- non-discriminatory selection of participants, e.g. women, children, minorities
  - informed consent
  - confidentiality of personal information
  - equitable access to information and benefits emanating from research
  - counselling, protection from discrimination, health and support services provided during and after participation
  - the establishment of local and/or national ethical review committees to ensure independent and ongoing ethical review, with participation by members of the community affected, of the research project
  - approval for use of safe and efficacious pharmaceuticals, vaccines and medical devices.
- (f) Antidiscrimination and protective laws should be enacted to reduce human rights violations against women in the context of HIV/AIDS, so as to reduce vulnerability of women to infection by HIV and to the impact of HIV/AIDS. In particular, laws should be reviewed and reformed to ensure equality of women regarding property and marital relations and access to employment and economic opportu-

nity, so that discriminatory limitations are removed on rights to own and inherit property, enter into contracts and marriage, obtain credit and finance, initiate separation or divorce, equitably share assets upon divorce or separation, and retain custody of children. Laws should also be enacted to ensure women's reproductive and sexual rights, including the right of independent access to reproductive and STD health information and services and means of birth control, including safe and legal abortion and the freedom to choose among these, the right to determine number and spacing of children, the right to demand safer sex practices and the right to legal protection from sexual violence, outside and inside marriage, including legal provisions for marital rape. The age of consent to sex and marriage should be consistent for males and females and the right of women and girls to refuse marriage and sexual relations should be protected by law. The HIV status of a parent or child should not be treated any differently from any other analogous medical condition in making decisions regarding custody, fostering or adoption.

- (g) Antidiscrimination and protective laws should be enacted to reduce human rights violations against children in the context of HIV/AIDS, so as to reduce the vulnerability of children to infection by HIV and to the impact of HIV/AIDS. Such laws should provide for children's access to HIV-related information, education and means of prevention inside and outside school, govern children's access to voluntary testing with consent by the child or by the parent or appointed guardian, as appropriate, should protect children against mandatory testing, particularly if orphaned by HIV/AIDS, and provide for other protections in the context of orphans, including inheritance and/or support. Such legislation should also protect children against sexual abuse, provide for their rehabilitation if abused and ensure that they are considered victims of wrongful behaviour, not subject to penalties themselves. Protection in the context of disability laws should also be ensured for children.
- (h) Antidiscrimination and protective laws should be enacted to reduce human rights violations against men having sex with men, including in the context of HIV/AIDS, in order, inter alia, to reduce the vulnerability of men who have sex with men to infection by HIV and to the impact of HIV/AIDS. These measures should include providing penalties for vilification of people who engage in same-sex relationships, giving legal recognition to same-sex marriages and/or relationships and governing such relationships with consistent property, divorce and inheritance provisions. The age of consent to sex and marriage should be consistent for heterosexual and homosexual relationships. Laws and police practices relating to assaults against men who have sex with men should be reviewed to ensure that adequate legal protection is given in these situations.
- (i) Laws and regulations that provide for restrictions on the movement or association of members of vulnerable groups in the context of HIV/AIDS should be removed in both law (decriminalized) and law enforcement.

- (j) Public health, criminal and antidiscrimination legislation should prohibit mandatory HIV testing of targeted groups, including vulnerable groups.

## Guideline 6: Regulation of goods, services and information

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States should enact legislation to provide for the regulation of HIV-related goods, services and information, so as to ensure widespread availability of qualitative prevention measures and services, adequate HIV prevention and care information and safe and effective medication at an affordable price.

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- (a) Laws and/or regulations should be enacted to enable implementation of a policy of widespread provision of information about HIV/AIDS through the mass media. This information should be aimed at the general public, as well as at various vulnerable groups that may have difficulties in accessing such information. HIV/AIDS information should be effective for its designated audience and not be inappropriately subject to censorship or other broadcasting standards.
- (b) Laws and/or regulations should be enacted to ensure the quality and availability of HIV tests and counselling. If home tests and/or rapid HIV test kits are permitted on the market, they should be strictly regulated to ensure quality and accuracy. The consequences of loss of epidemiological information, the lack of accompanying counselling and the risk of unauthorized uses, such as for employment or immigration, should also be addressed. Legal and social support services should be established to protect individuals from abuses arising from such testing.
- (c) Legal quality control of condoms should be enforced and compliance with the International Condom Standard should be monitored in practice. Restrictions on the availability of preventive measures, such as condoms, bleach, clean needles and syringes, should be repealed and the provision of these through vending machines in appropriate locations should be considered, in the light of the increased accessibility and anonymity afforded to clients by this method of distribution.
- (d) Duties, customs laws and value-added taxes should be revised so as to maximize access to safe and effective medication at an affordable price.



- (e) Consumer protection laws or other relevant legislation should be enacted or strengthened to prevent fraudulent claims regarding the safety and efficacy of drugs, vaccines and medical devices, including those relating to HIV/AIDS.

## Guideline 7: Legal support services

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

States should consider the following features in establishing such services:

- (a) State support for legal aid systems specializing in HIV/AIDS casework, possibly involving community legal aid centres and/or legal service services based in ASOs;
- (b) State support or inducements (e.g. tax reduction) to private sector law firms to provide free pro bono services to PLWHAs in areas such as antidiscrimination and disability, health care rights (informed consent and confidentiality), property (wills, inheritance) and employment law;
- (c) State support for programmes to educate, raise awareness and build self-esteem among PLWHAs concerning their rights and/or to empower them to draft and disseminate their own charters/declarations of legal and human rights; State support for production and dissemination of HIV/AIDS legal rights brochures, resource personnel directories, handbooks, practice manuals, student texts, model curricula for law courses and continuing legal education, and newsletters to encourage information exchange and networking should also be provided. Such publications could report on case law, legislative reforms, national enforcement and monitoring systems for human rights abuses;
- (d) State support for HIV legal services and protection through a variety of offices, such as Ministries of Justice, procurator and other legal offices, health complaint units, ombudspersons and human rights commissions.

## (C) Promotion of a Supportive and Enabling Environment

### Guideline 8: Women, children and other vulnerable groups

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States should, in collaboration with and through the community, promote a supportive and enabling environment for women, children and other vulnerable groups by addressing underlying prejudices and inequalities through community dialogue, specially designed social and health services and support to community groups.

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- (a) States should support the establishment and sustainability of community associations comprised of members of different vulnerable groups for peer education, empowerment, positive behaviour change and social support.
- (b) States should support the development of adequate, accessible and effective HIV-related prevention and care education, information and services by and for vulnerable communities and should actively involve these communities in the design and implementation of these programmes.
- (c) States should support the establishment of national and local forums to examine the impact of the HIV/AIDS epidemic on women. They should be multisectoral to include government, professional, religious and community representation and leadership and examine issues such as:
  - the role of women at home and in public life
  - the sexual and reproductive rights of women and men, including women's ability to negotiate safer sex and make reproductive choices
  - strategies for increasing educational and economic opportunities for women
  - sensitizing service deliverers and improving health care and social support services for women
  - the impact of religious and cultural traditions on women.

- (d) States should implement the Cairo Programme of Action of the International Conference on Population and Development and the Beijing Declaration and Platform for Action of the Fourth World Conference on Women. In particular, primary health services, programmes and information campaigns should contain a gender perspective. Harmful traditional practices, including violence against women, sexual abuse, exploitation, early marriage and female genital mutilation, should be eliminated. Positive measures, including formal and informal education programmes, increased work opportunities and support services, should be established.
- (e) States should support women's organizations to incorporate HIV/AIDS and human rights issues into their programming.
- (f) States should ensure that all women and girls of child-bearing age have access to accurate and comprehensive information and counselling about the prevention of HIV transmission and the risk of vertical transmission of HIV, as well as access to the available resources to minimize that risk, or to proceed with childbirth, if they so choose.
- (g) States should ensure the access of children and adolescents to adequate health information and education, including information related to HIV/AIDS prevention and care, inside and outside school, which is tailored appropriately to age level and capacity and enables them to deal positively and responsibly with their sexuality. Such information should take into account the rights of the child to access to information, privacy, confidentiality, respect and informed consent and means of prevention, as well as the responsibilities, rights and duties of parents. Efforts to educate children about their rights should include the rights of persons, including children, living with HIV/AIDS.
- (h) States should ensure that children and adolescents have adequate access to confidential sexual and reproductive health services, including HIV/AIDS information, counselling, testing and prevention measures such as condoms, and to social support services if affected by HIV/AIDS. The provision of these services to children/adolescents should reflect the appropriate balance between the rights of the child/adolescent to be involved in decision-making according to his or her evolving capabilities and the rights and duties of parents/guardians for the health and well-being of the child.
- (i) States should ensure that child care agencies, including adoption and foster care homes, are trained with regard to HIV-related children's issues in order to be able to take into account the special needs of HIV-affected children and protect them from mandatory testing, discrimination and abandonment.

- (j) States should support the implementation of specially designed and targeted HIV prevention and care programmes for those who have less access to mainstream programmes due to language, poverty, social or legal or physical marginalization, e.g. minorities, migrants, indigenous peoples, refugees and internally displaced persons, people with disabilities, prisoners, sex workers, men having sex with men and injecting drug users.

## Guideline 9: Changing discriminatory attitudes through education, training and the media

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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.

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- (a) States should support appropriate entities, such as media groups, NGOs and networks of PLWHAs, to devise and distribute programming to promote respect for the rights and dignity of PLWHAs and members of vulnerable groups, using a broad range of media (film, theatre, television, radio, print, dramatic presentations, personal testimonies, Internet, pictures, bus posters). Such programming should not compound stereotypes about these groups but instead dispel myths and assumptions about them by depicting them as friends, relatives, colleagues, neighbours and partners. Reassurance concerning the modes of transmission of the virus and the safety of everyday social contact should be reinforced.
- (b) States should encourage educational institutions (primary and secondary schools, universities and other technical or tertiary colleges, adult and continuing education), as well as trade unions and workplaces to include HIV/AIDS and human rights/non-discrimination issues in relevant curricula, such as human relationships, citizenship/social studies, legal studies, health care, law enforcement, family life and/or sex education, and welfare/counselling courses.
- (c) States should support HIV-related human rights/ethics training/workshops for government officials, police, prison staff, politicians, as well as village, community and religious leaders and professionals.
- (d) States should encourage the media and advertising industries to be sensitive to HIV/AIDS and human rights issues and to reduce sensationalism in reporting and inappropriate use of stereotypes, especially in relation to disadvantaged and vul-

nerable groups. Included in such training should be the production of useful resources, such as handbooks containing appropriate terminology, to eliminate use of stigmatizing language and a professional code of behaviour to ensure respect for confidentiality and privacy.

- (e) States should support targeted training, peer education and information exchange for PLWHA staff and volunteers of CBOs and ASOs and leaders of vulnerable groups to raise their awareness of human rights and the means to enforce them. Conversely, education and training should be provided on HIV-specific human rights issues to those working on other human rights issues.
- (f) States should support the use of alternative efforts such as radio programmes or facilitated group discussions to overcome access problems for individuals who are located in remote or rural areas, illiterate, homeless or marginalized, without access to television, films and videos, and specific ethnic minority languages.

## Guideline 10: Development of public and private sector standards and mechanisms for implementing these standards

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.

- (a) States should require or encourage professional groups, particularly health-care professionals, and other private sector industries (e.g. law, insurance) to develop and enforce their own codes of conduct addressing human rights issues in the context of HIV/AIDS. Relevant issues would include confidentiality, informed consent to testing, the duty to treat, the duty to ensure safe workplaces, reducing vulnerability and discrimination and practical remedies for breaches/misconduct.
- (b) States should require individual government portfolios to articulate how HIV-related human rights standards are met in their own policies and practices, as well as in formal legislation and regulations, at all levels of service delivery. Coordination of these standards should occur in the national framework described in Guideline 1 and be publicly available, after involvement of community and professional groups in the process.

- (c) States should develop or promote multisectoral mechanisms to ensure accountability. This involves the equal participation of all concerned (i.e. government agencies, industry representatives, professional associations, NGOs, consumers, service providers and service users). The common goal should be to raise standards of service, strengthen linkages and communication and assure the free flow of information.

## Guideline 11: State monitoring and enforcement of human rights

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States should ensure monitoring and enforcement mechanisms to guarantee HIV-related human rights, including those of people living with HIV/AIDS, their families and communities.

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- (a) States should collect information on human rights and HIV/AIDS and, using this information as a basis for policy and programme development and reform, report on HIV-related human rights issues to the relevant United Nations treaty bodies as part of their reporting obligations under human rights treaties.
- (b) States should establish HIV/AIDS focal points in relevant government branches, including national AIDS programmes, police and correctional departments, the judiciary, government health and social service providers and the military, for monitoring HIV-related human rights abuses and facilitating access to these branches for disadvantaged and vulnerable groups. Performance indicators or benchmarks showing specific compliance with human rights standards should be developed for relevant policies and programmes.
- (c) States should provide political, material and human resources support to ASOs and CBOs for capacity-building in human rights standards development and monitoring. States should provide human rights NGOs with support for capacity-building in HIV-related human rights standards and monitoring.
- (d) States should support the creation of independent national institutions for the promotion and protection of human rights, including HIV-related rights, such as human rights commissions and ombudspersons, and/or appoint HIV/AIDS ombudspersons to existing or independent human rights agencies, national legal bodies and law reform commissions.
- (e) States should promote HIV-related human rights in international forums and ensure that they are integrated into the policies and programmes of international

organizations, including in United Nations human rights bodies, as well as in other agencies of the United Nations system. Furthermore, States should provide intergovernmental organizations with the material and human resources required to work effectively in this field.

## Guideline 12: International cooperation

States should cooperate through all relevant programmes and agencies of the United Nations system, including UNAIDS, to share knowledge and experience concerning HIV-related human rights issues, and should ensure effective mechanisms to protect human rights in the context of HIV/AIDS at the international level.

- (a) The Commission on Human Rights should take note of the present Guidelines and of the report on the Second International Consultation on HIV/AIDS and Human Rights and request States to carefully consider and implement the Guidelines in their national, subnational and local responses to HIV/AIDS and human rights.
- (b) The Commission on Human Rights should request human rights treaty bodies, special rapporteurs and representatives and its working groups to take note of the Guidelines and include in their activities and reports all issues arising under the Guidelines relevant to their mandates.
- (c) The Commission on Human Rights should request UNAIDS, its Cosponsors (UNICEF, UNDP, UNFPA, UNDCP, UNESCO, WHO and the World Bank) and other relevant United Nations bodies and agencies to integrate the promotion of the Guidelines throughout their activities.
- (d) The Commission on Human Rights should appoint a special rapporteur on human rights and HIV/AIDS with the mandate, inter alia, to encourage and monitor implementation of the Guidelines by States, as well as their promotion by the United Nations system, including human rights bodies, where applicable.
- (e) The Commission on Human Rights should encourage the United Nations High Commissioner/Centre for Human Rights to ensure that the Guidelines are disseminated throughout his Office and the Centre and are incorporated into all its human rights activities and programmes, particularly those involving technical cooperation, monitoring and support to human rights bodies and organs.

- (f) States, in the framework of their periodic reporting obligations to United Nations treaty monitoring bodies and under regional conventions, should report on their implementation of the Guidelines and other relevant HIV/AIDS-related human rights concerns arising under the various treaties.
- (g) States should ensure, at the country level, that their cooperation with UN Theme Groups on HIV/AIDS includes promotion and implementation of the Guidelines, including the mobilization of sufficient political and financial support for such implementation.
- (h) States should work in collaboration with UNAIDS, the United Nations High Commissioner for Human Rights and nongovernmental and other organizations working in the field of human rights and HIV/AIDS to:
- support translation of the Guidelines into national and minority languages
  - create a widely accessible mechanism for communication and coordination for sharing information on the Guidelines and HIV-related human rights
  - support the development of a resource directory on international declarations/treaties, as well as policy statements and reports on HIV/AIDS and human rights, to strengthen support for the implementation of the Guidelines
  - support multicultural education and advocacy projects on HIV/AIDS and human rights, including educating human rights groups on HIV/AIDS and educating HIV/AIDS service organizations and vulnerable groups on human rights issues, and strategies for monitoring and protecting human rights in the context of HIV/AIDS, using the Guidelines as an educational tool
  - support the creation of a mechanism to allow existing human rights organizations and HIV/AIDS organizations to work together strategically to promote and protect the human rights of people living with HIV/AIDS and those vulnerable to infection, including through implementation of the Guidelines
  - support the creation of a mechanism to monitor and publicize human rights abuses in the context of HIV/AIDS
  - support the development of a mechanism to mobilize grass-roots responses to HIV-related human rights and implementation of the Guidelines, including exchange programmes and training among different communities, both within and across regions
  - advocate that religious and traditional leaders take up HIV-related human rights concerns and become part of the implementation of the Guidelines



- support the development of a manual that would assist human rights and AIDS service organizations in advocating for the implementation of the Guidelines
  - support the identification and funding of NGOs and ASOs at country level to coordinate a national NGO response to promote the Guidelines
  - support, through technical and financial assistance, national and regional NGO networking initiatives on ethics, law and human rights to enable them to disseminate the Guidelines and advocate for their implementation.
- (i) States, through regional human rights mechanisms, should promote the dissemination and implementation of the Guidelines and their integration into the work of these bodies.

## ANNEX D

### About UNAIDS

UNAIDS is the Joint United Programme on HIV/AIDS cosponsored by seven UN-system agencies – UNICEF, UNDP, UNFPA, UNDCP, UNESCO, WHO and the World Bank. It commenced operations in January 1996. UNAIDS is founded on the concept of an expanded response to HIV/AIDS in which UN agencies and other relevant actors can contribute their expertise and address those issues which are relevant to their mandate. The Strategic Plan 1996-2000 stated:

**“A joint programme bringing together UN organisations with complementary mandates and expertise was thought to be warranted by the epidemic’s urgency and magnitude, its complex socioeconomic and cultural roots, the denial and complacency surrounding HIV and its routes of transmission and the discrimination and human rights violations faced by those infected or threatened by HIV... HIV tends to spread along the pre-existing fault lines of society fuelled by societal and structural factors such as poverty, disorder, discrimination and the subordinate status of women.”**

Human rights is a cross-cutting theme for UNAIDS, and the 1998-99 Workplan identifies the area of human rights, ethics and law as an integral part of the Programme. A human rights based response to HIV/AIDS safeguards human dignity and enables communities and individuals to respond effectively to HIV/AIDS, and provides a legal and ethical framework to facilitate equal access to prevention and care programmes.

Over a third of UNAIDS staff are posted in selected countries with 38 Country Programme Advisers and 14 InterCountry Technical Advisers servicing UN Theme Groups on HIV/AIDS. These are established at country level by the Resident Coordinator, usually from UNDP, and include national government as well as UNAIDS Cosponsor representatives. The UN Theme Groups are coordination mechanisms which enable countries to make the best use of the UN system to support their national HIV/AIDS Programmes.

It is UNAIDS task to coordinate, strengthen and support all UN activities aimed at preventing transmission of HIV, providing care and support, reducing the vulnerability of individuals and communities to HIV, and alleviating the impact of the epidemic. It has a catalytic role in forming partnerships with relevant actors such as the IPU.

Although UNAIDS does not have a direct implementation role, it can influence policy making through:

- its convening power, which can result in the setting of standards;
- its advocacy role at global and country level; and
- its ability to offer technical expertise to actors such as governments. One aspect of this function is the development of best practice materials that identify, develop and collect real examples of principles, strategies, policies and activities that work, and are recognized to be technically, ethically and strategically sound, sustainable and replicable.

The address of the UNAIDS web-site is: <http://www.unaids.org>

## ANNEX E

### About the Inter-Parliamentary Union

The Inter-Parliamentary Union (“IPU”) was established in 1889 as the world organization of parliaments of sovereign states, and was the first permanent forum for political multilateral negotiations. At the end of 1999, 139 national parliaments were members, and five international parliamentary assemblies were associate members. Finance for the IPU is provided by its members out of public funds, and its headquarters is in Geneva, Switzerland.

The IPU brings together the representatives of national parliaments for the study of political, economic, social and cultural problems of international significance. It is the focal point for worldwide parliamentary dialogue, and works for peace and cooperation among peoples and for the firm establishment of representative democracy. The IPU supports the efforts of the United Nations, whose objectives it shares, and works in close cooperation with, in respect of their complementary roles. In July 1996 the IPU concluded a Co-operation Agreement with the UN to strengthen relations between the two world organizations, and it was welcomed in October 1996 by the UN General Assembly.

The IPU fosters contacts, coordination, and the exchange of experience among parliaments and parliamentarians of all countries. It considers questions of international interest and concern, and expresses its views on such issues in order to bring about action by parliaments and parliamentarians. It contributes to the defence and promotion of human rights – an essential factor of parliamentary democracy and development. Finally, it contributes to better knowledge of the working of representative institutions and to the strengthening and development of their means of action.

The Statutory Conference of the IPU meets twice a year at different venues and it is the principal statutory organ that expresses the views of the IPU. Delegations attending the conference customarily include members of parliament from all parties. Voting rights vary according to a State’s populations, and votes can be split to reflect the different opinions of delegation members. Four plenary study committees assist the conference in its work, one of which is the Committee on Education, Science, Culture and the Environment. This Handbook was drafted with the assistance of that Committee.

IPU members submit to their respective assemblies and governments the recommendations adopted by the IPU at its conferences and promote their implementation. Numerous measures of a legislative, policy or technical nature have been taken all over the world as a result. At the 87th IPU Conference in Yaoundé, Cameroon, a resolution was adopted on the pandemic nature of AIDS and its threat to world economic growth, political and social stability, and the promotion of policies to transform sci-

entific knowledge into public policy and social and political commitment to mitigate its effect. A follow-up resolution was made at the 99th Conference in Windhoek, Namibia, on action to combat HIV/AIDS in view of its devastating human, economic and social impact. This Handbook was developed in accordance with that resolution.

The address of the IPU web-site is: <http://www.ipu.org>

## ENDNOTES

- <sup>1</sup> *AIDS epidemic update*, December 1998, UNAIDS and WHO.
- <sup>2</sup> *The Business Response to HIV/AIDS: Innovation and Partnership*, UNAIDS and Prince of Wales Business Leaders' Forum, Geneva and London, 1997, section 1, p. 9.
- <sup>3</sup> Speth JG., *Human Rights and Sustainable Human Development*, Management Development and Governance Division, Bureau for Development Policy, UNDP, November 1997 and *Governance for Sustainable Human Development: UNDP Policy Document*, January 1997.
- <sup>4</sup> *Namibian Human Development Report: The Impact of HIV and AIDS in Namibia*, UNDP with UNAIDS Cosponsors, 1997, Chapter 6.
- <sup>5</sup> The 30-year project which began in 1998 involves the use of 2,000 workers, usually single unaccompanied males living in barracks and 400-600 truckers – *Confronting AIDS: Public Priorities in a Global Epidemic*, A World Bank Policy Research paper, 1998, Box 1.3.
- <sup>6</sup> WHO/UNAIDS/HLE/97.1.
- <sup>7</sup> According to UNAIDS best practice means accumulating and applying knowledge about what is working or not working in AIDS prevention, care and support projects and programmes in different situations and contexts. It is the lessons learned, as well as the continuous process of learning, feedback, reflection and analysis of practices which are sound, ethical, effective, responsive and replicable. Collection, production, dissemination and promotion of such data enable it to be shared and lessons learnt before adaptation to other countries or regions.
- <sup>8</sup> Kimble M. A/g Assistant Secretary, Bureau of Oceans and International Environmental and Scientific Affairs, US State Department, speech entitled "Political Will in the Response to the AIDS Epidemic", to National Council on International Health, Washington D.C, 25 June 1998.
- <sup>9</sup> Logan D. *The Business Response to HIV/AIDS: Innovation and Partnership*, UNAIDS and the Prince of Wales Business Leaders' Forum, Geneva and London, 1997.
- <sup>10</sup> *The Action Brief*, UNAIDS, December 1998.
- <sup>11</sup> UNAIDS. *Expanding the global response to HIV/AIDS through focused action – Reducing risk and vulnerability: definitions, rationale and pathways*, Key Material, Best Practice Collection, 1998.
- <sup>12</sup> Commencement Address, Morgan State University, Baltimore, Maryland on 18 May 1998.
- <sup>13</sup> UNAIDS. *The Action Brief*, February 1999.
- <sup>14</sup> Personal communication with Rita Arauz, Fundación Nimehuatzin, 9 June 1998.
- <sup>15</sup> The SHAKTI project of CARE funded by DFID.
- <sup>16</sup> In March 1996 a workshop sponsored by UNAIDS was held in New Delhi by the Parliamentarians' Forum for Human Development on AIDS: Approaches to

- Prevention – papers and proceedings edited by Dr N. Heptulla. A global conference, AIDS – Law and Humanity, was held by the Indian Law Institute in December 1995 in New Delhi, India which was opened by the President and Prime Minister, as well as several Cabinet Ministers.
- 17 AIDS workshops were held for 35 parliamentarians of the Population and Social Development Committee in September 1997 and August 1998 by the National Center for AIDS and STD Control funded by UNAIDS.
- 18 The Health Commission held an International Forum on HIV/AIDS and Legislative Challenge in Mexico for the Lower Chamber of the National Congress.
- 19 The Malawi Cabinet Sub-committee on HIV/AIDS has a Parliamentary Caucus for Women.
- 20 Whelan D. “Human Rights Approaches to an Expanded Response to Address Women’s Vulnerability to HIV/AIDS” *Health and Human Rights* (1998) 3(1), 21 at 23.
- 21 Mann J. and Tarantola D. “Responding to HIV/AIDS: A Historical Perspective” *Health and Human Rights* (1998) 2(4), 5.
- 22 E/CN.4/1997/37.
- 23 1997/33.
- 24 1997/40.
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- 26 Gostin L and Lazzarini L. *Human Rights and Public Health in the AIDS Pandemic*, Oxford University Press, New York, 1997, p. 4.
- 27 Adopted at the World Conference on Human Rights, A/CONF.157/24 ( Part I), Chap. III. See also the Declaration on the Right to Development.
- 28 Craven MCR. *The International Covenant on Economic, Social and Cultural Rights: A Perspective on its Development*, Clarendon Press, Oxford, 1995, p. 109.
- 29 UN Commission on Human Rights Resolution 1996/44 and also Resolution 1995/21 of the Sub-Commission on the Prevention of Discrimination and Protection of Minorities.
- 30 Siracusa Principles E/CN.4/1984/4.
- 31 Sieghart P. *AIDS and Human Rights: A UK Perspective*, British Medical Foundation for AIDS, London, 1989.
- 32 This could include provincial/State as well as national representation in federal systems.
- 33 *Connecting lower HIV infection rates with changes in sexual behaviour in Thailand*, UNAIDS Case Study, June 1998.
- 34 *Citizen*, 23 October 1997.
- 35 Street J and Weale A. “ Britain: Policy-making in a Hermetically Sealed System” in Kirp D. and Bayer R. (eds.) *AIDS in the Industrialized Democracies – Passions, Politics and Policies*, Rutgers University Press, New Brunswick, 1992, p. 185.
- 36 UNAIDS, *Expanding the global response to HIV/AIDS through focused action*, Key Material, Best Practice Collection, 1998.
- 37 *Ibid.*, p.207.
- 38 Ballard J. “Australia: Participation and Innovation in a Federal System” *ibid.*, p. 144

- <sup>39</sup> Marchant P. “The British Parliamentary Experience” speech to the Standing Conference of European Parliamentarians on HIV/AIDS, 19-20 May 1995, Barcelona, Spain, *Conference Report*, p. 80.
- <sup>40</sup> All-Party Parliamentary Group on AIDS, *Annual Review*, 1996, p.3.
- <sup>41</sup> *Ibid* and *Annual Review* 1995.
- <sup>42</sup> See Watchirs H. “Law Reform in Australia: The Legal Working Party, Intergovernmental Committee on AIDS” in Wiseberg L. *Human Rights and HIV/AIDS: Effective Community Responses*, Human Rights Internet (funded by UNAIDS), Ottawa, 1998
- <sup>43</sup> Wiseberg L. (ed.), *Human Rights and HIV/AIDS: Effective Community Responses*, Human Rights Internet (funded by UNAIDS), Ottawa, 1998.
- <sup>44</sup> Impetus for the initiative came from: senior national and regional officials; a realization that the epidemic was rapidly expanding as shown by dramatic sentinel surveillance findings; compelling evidence of the value of decentralization by the external assistance community; and pressure from a forum convened during the 3rd International Conference on AIDS in Asia and the Pacific in Chiang Mai. – Dr Wiwat Rojanapithayakorn and Mr P. Cox, “Interim Results of a Case Study from Northern Thailand - Governance and HIV, Decentralisation” presented at the 4th International Congress on AIDS in Asia and the Pacific, Manila, October 1997.
- <sup>45</sup> This being the first time that budget was provided to a programme not belonging to any government ministry.
- <sup>46</sup> Maatin A. *Governance and HIV – A Discussion Paper*, Second Draft, UNDP Regional Governance Facility, Islamabad 1997, pp. 5 and 13.
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**Joint United Nations Programme on HIV/AIDS (UNAIDS)**  
20 avenue Appia, 1211 Geneva 27, Switzerland  
Tel. (+4122) 791 46 51 – Fax (+4122) 791 41 65  
e-mail: [unaids@unaids.org](mailto:unaids@unaids.org) – Internet: <http://www.unaids.org>