Programming HIV/AIDS:
a human rights approach

A tool for international development and community-based organizations responding to HIV/AIDS

Canadian version

Prepared by
David Patterson, Consultant
Canadian HIV/AIDS Legal Network

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Preface

International legal obligations and sound public health practice require that to reduce the spread and impact of HIV/AIDS, policies and programs must protect and promote human rights. The human rights approach offers a potentially effective, globally integrated framework for addressing the underlying determinants of HIV infection, care and impact over the longer term. However in practice, difficulties arise in the design and delivery of human rights-based HIV/AIDS programs often because:

- some funders and development organizations are still considering what a human rights approach means for HIV/AIDS programming;
- human rights, democracy and governance programs and projects often focus on civil and political rights, including issues such as media freedom and free and fair elections, and rarely include an HIV/AIDS perspective; and
- the experience of human rights programming in the context of HIV/AIDS has not been adequately documented.

Research for this publication commenced in 2001 when the Canadian International Development Agency (CIDA) approached the Canadian HIV/AIDS Legal Network for practical guidance in incorporating human rights approaches into development programming on HIV/AIDS. A survey of other government and agency approaches was undertaken by the author (*Reviewing programming on HIV/AIDS, human rights and development,* 2002), which suggested that a manual which combined international human rights principles, guidelines, and emerging best practice would be a useful tool for development staff in national government, inter-governmental and non-government organizations and other funders supporting national and international responses to HIV/AIDS.

International development funding for HIV/AIDS, and for sexual and reproductive health more broadly, continues to be influenced by considerations other than good science, sound public health and development best practice, and accepted principles of international law. All the more reason, therefore, to document, publicize and demonstrate the practical application of human rights approaches, and to monitor and evaluate their short and longer term impact.

Of course, the human rights approach to development (which emphasizes participation and inclusion, non-discrimination and equality, accountability and transparency, and indivisibility and interdependence) provides a framework for development theory and practice beyond HIV/AIDS. The author hopes that exploring the application of human rights approaches to a major development challenge such as HIV/AIDS can stimulate the integration of these approaches in other areas of health, the environment and development.

Who is this tool for?

The tool was prepared with reference to Government of Canada policies and practices, and the primary audience is program staff in Canada in
- non-governmental development organizations
- community based AIDS organizations
- the private sector

who prepare funding proposals, and manage and evaluate projects or programs, which address HIV/AIDS and related issues in developing countries and countries in transition.

The tool will also be of interest to people in other donor countries undertaking similar work, including staff of inter-governmental and development agencies, who fund or manage HIV/AIDS and related programs.

The principles, approaches and examples provided should be of interest to people working in other areas of development not directly related to HIV/AIDS and who are seeking to incorporate human rights approaches in their work.

Comments on this version

Comments on ways to improve this tool are welcome. Please write to the author, David Patterson (email: david.patterson@videotron.ca).

Executive Summary

In order to be effective and sustainable, national and international responses to the HIV/AIDS epidemic must aim to limit the immediate spread and impact of HIV/AIDS, and also address the underlying determinants of infection and impact. Like gender equality, appropriate analysis and responses to HIV/AIDS must be mainstreamed throughout development assistance programming. Programs which respect, protect and fulfill human rights in the context of HIV/AIDS are consistent with international law as well as emerging good practice in international development assistance.

This programming tool is designed to facilitate the integration of human rights approaches into development programming on HIV/AIDS. The tool builds on work to assess the advantages and implications of human rights approaches to development assistance generally, and provides practical guidance in translating international human rights principles and legal obligations into practical programming at country level.

The tool sets out the international legal and policy environment, noting Canada's commitments. It then identifies four key principles of a human rights approach to development, and examines how they apply to HIV/AIDS programming. Practical aspects of program design, implementation and evaluation are discussed, and useful checklists provided. The tool then reviews some lessons learned from human rights HIV/AIDS programming, and gives some good practice examples of programs and projects in different regions. It concludes with resources and web sites for further information.

1.   Legal and policy environment

International legal framework

The human rights dimensions of the HIV/AIDS epidemic span the full range of civil, political, economic, social, and cultural rights, and include:

- direct discrimination against people living with HIV/AIDS or presumed to be infected (e.g. denial of the rights to work, to housing or to medical attention based on HIV status);
- factors that increase vulnerability to HIV infection, or the impact it has if infection occurs (e.g. denial of the rights to adequate food, to education, to treatment of disease (including sexually transmitted infections), and gender-based discrimination); and
- factors limiting the civil society response to the HIV epidemic (e.g. denial of the rights to freedom of speech and association for affected groups; police or other harassment of HIV prevention education workers).

Customary international law and international legal treaties form the basis of the international law of human rights. Key treaties include the International Covenant on Economic, Social and Cultural Rights; the International Covenant on Civil and Political Rights; the Convention on the Elimination of all forms of Discrimination against Women; the Convention on the Rights of the Child; and the International Convention on the Elimination of All Forms of Racial Discrimination. Regional treaties in Europe, Africa and the Americas are also relevant, as are the treaties of the International Labour Organization (ILO) on issues such as workplace discrimination. Other sources include the general comments and other statements of the UN treaty committees, the resolutions of the Commission on Human Rights, and the writings of international experts.

Human rights relevant to HIV/AIDS include:
- The right to non-discrimination, equal protection and equality before the law;
- The right to life;
- The right to the highest attainable standard of physical and mental health;
- The right to liberty and security of person;
- The right to freedom of movement;
- The right to seek and enjoy asylum;
- The right to privacy;
- The right to freedom of opinion and expression and the right to freely receive and impart information;
- The right to freedom of association;
- The right to work;
- The right to marry and to found a family;
- The right to equal access to education;
- The right to an adequate standard of living;
- The right to social security, assistance and welfare;
- The right to share in scientific advancement and its benefits;
- The right to participate in public and cultural life;
- The right to be free from torture and cruel, inhuman or degrading treatment or punishment.

(*HIV/AIDS and Human Rights: International Guidelines* para. 80)

Progressive implementation

International law recognizes that some rights, such as those relating to universal education or health care, must necessarily be achieved progressively in resource poor settings. Even among these rights, there are 'core obligations' (such as essential primary health care, basic housing and education) which should be met immediately. In all cases, States should take deliberate, concrete and targeted steps to meeting their legal obligations. States should also immediately adopt legislation to ensure that services are provided without discrimination of any kind, if this legislation does not yet exist (Committee on Economic, Social and Cultural Rights, General Comment 3 (1990)).

Limitations on rights in order to protect public health

International law provides that certain rights (such as the right to freedom of movement or expression) can be limited to protect public health, but only after strict tests have been satisfied. The **Siracusa Principles** require the State to establish that the limitation is:

 a) provided for and carried out in accordance with the law,
 b) based on a legitimate interest,
 c) proportional to that interest and constituting the least intrusive and least restrictive measure available, and
 d) actually achieving that interest in a democratic society.

Some rights (such as the right to life, freedom from torture, and freedom of thought) cannot be limited on public health or any other grounds.
(*HIV/AIDS and Human Rights: International Guidelines*, para. 82)

Example: Public health and the limits of the right to privacy

How should health care workers respond if they believe a person living with HIV/AIDS is continuing to put others at risk? In 1996 the international expert committee drafting the International Guidelines on HIV/AIDS and Human Rights applied the Siracusa Principles to this challenge. They recommended that public health legislation should authorize, but not require, that health care professionals decide, on the basis of each individual case and ethical considerations, whether 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 possible in practice;
- Follow-up is provided to ensure support to those involved, as necessary.

(*HIV/AIDS and Human Rights: International Guidelines*, para. 28(g))

Example: Public health and the right to work
HIV infection is not transmitted casually, and occupational transmission can be prevented by the use of Standard Precautions to protect against all blood-borne infections. Therefore restrictions on the employment of persons living with HIV cannot generally be justified on public health grounds. States must ensure public health legislation does not inappropriately list HIV with contagious diseases, and should introduce and enforce legislation to prohibit discrimination in employment. Workplace training and mechanisms must be in place to ensure that policies are understood and respected. (*Code of Practice on HIV/AIDS and the World of Work*, 2001). *Program staff should examine proposals which would limit human rights on public health or other grounds, and may wish to seek advice as to whether these limitations satisfy the Siracusa Principles.*

Right to the highest attainable standard of health

The 'right to health' is an important component of a human rights approach to HIV/AIDS. The right to health includes the right to health care, embraces a wide range of socio-economic factors that promote conditions in which people can lead a healthy life, and extends to the underlying determinants of health, such as food and nutrition, housing, access to safe and potable water and adequate sanitation, safe and healthy working conditions, and a healthy environment. This includes the right to 'sexual and reproductive health services,… access to information, as well as the resources necessary to act on that information' (Committee on Economic, Social and Cultural Rights, General Comment 14 (2000)). States also have specific responsibility for public health, including the prevention, treatment and control of epidemic diseases such as HIV/AIDS. Core obligations in this context include the provision of essential drugs to treat HIV/AIDS. (See *Guidelines for Supporting HIV/AIDS Care, Treatment, and Support in Resource Limited Settings* (Ottawa: CIDA, 2004)).

Finally, the human rights approach to health can be considered both an objective (safeguarding human dignity), and a means to achieving goals (providing an enabling environment). Thus both *processes* (e.g. participation, transparency, accountability) and *substantive elements* (e.g. paying attention to vulnerable groups, using a gender perspective, ensuring freedom from discrimination, disaggregating health data, and promoting education and information) are involved in the human rights approach.

Example: access to HIV treatments in resource poor countries
Botswana and South Africa have both declared their commitment to provide universal access to antiretroviral therapy (ART). Many other countries are exploring ways to roll out ART. The WHO goal of three million people in developing countries receiving ART by 2005 is another example of progressive implementation. *Program staff should be aware of international commitments and initiatives supported by Canada when designing, reviewing or implementing programs which include a health care component, and look for opportunities to support these commitments and initiatives.*

International Guidelines on HIV/AIDS and Human Rights

The International Guidelines on HIV/AIDS and Human Rights translate international human rights norms into practical action in the context of HIV/AIDS. The Guidelines are 12 short principles (see Annex) – the accompanying commentary provides substantial guidance on their implementation. They were draft in 1996 by an expert group (which included government officials and staff of national AIDS programs, people living with HIV/AIDS, human rights experts, and others) and partly revised in 2002. Additional resources have been developed to assist in the implementation of the Guidelines (see section 7).

Example: Using the International Guidelines as a framework for dialogue
The National AIDS Committee (NAC) of Guyana comprises representatives of the National AIDS Programme, people living with HIV/AIDS, and human rights and other non-governmental organizations fighting HIV/AIDS. The NAC uses the International Guidelines on HIV/AIDS and Human Rights as a framework for its consultations with diverse communities and its submissions to the Government of Guyana on legal, policy and program reforms relating to HIV/AIDS. In 2004 CARICOM, with CIDA funding, supported a human rights assessment of law and policy relating to HIV/AIDS in Guyana based on the International Guidelines as part of a regional programme on HIV/AIDS, law, ethics and human rights. *Program staff should be aware of and support local initiatives to apply human rights approaches to HIV/AIDS.*

CIDA's policy environment

The *Government of Canada Policy for CIDA on Human Rights, Democratization and Good Governance* (1996) sets out CIDA's commitment to strengthen civil society, including popular participation; democratic institutions; public sector competence; human rights organizations; and political will to respect rights, rule democratically, and govern effectively.

Human rights approaches are consistent with CIDA's evolving policy directions, as set out in *Strengthening Aid Effectiveness* (2002). This includes an emphasis on local ownership, good governance and a sound policy environment. The Millennium Development Goals refer specifically to HIV/AIDS (MDG 6), and HIV/AIDS is one of CIDA's four social development priorities.

Human rights approaches to HIV/AIDS are consistent with CIDA's revised development assistance planning and delivery methodology - the CIDA Business Process Roadmap - and support development, enabling and management results – CIDA's Key Agency Results (KARs).

CIDA's HIV/AIDS Action Plan (2000) notes in its guiding principles 'promoting increased linkages between HIV/AIDS and basic education, human rights and good governance', 'promoting sustainable development and poverty reduction through a broad development approach, including…human rights', and 'consistency with international guidelines on HIV and human rights.'

In 2002 Canada endorsed the United Nations' *Declaration of Commitment on HIV/AIDS*, and has participated actively in the follow up and implementation of the Declaration. CIDA has also developed programming guidelines in specific areas, such as the *Guidelines for Supporting HIV/AIDS Care, Treatment, and Support in Resource Limited Settings* (Ottawa: CIDA, 2004). The principle of policy coherence, emphasized in *Strengthening Aid Effectiveness,* requires that CIDA's development assistance be consistent with Canada's public commitments on HIV/AIDS, and human rights.

Example: monitoring the implementation of the UNGASS Declaration
Governments are requested to report annually on the implementation of the United Nations General Assembly (UNGASS) Declaration of Commitment on HIV/AIDS. Canada's report is prepared in consultation with all relevant departments and agencies, including CIDA. In 2003 UNAIDS published all the country reports (over 100) on its website. *Program staff can review country reports when assessing country situations for the design and review of HIV/AIDS programming. (www.unaids.org – go to Events (left column)>Follow up to the 2001 Special Session (right column) – September 2003>UNGASS national progress reports (in centre text)). Information should be cross-checked with independent sources.*

2.   Principles of human rights approaches

The following principles are based on the international law of human rights (noted above).

Participation and inclusion

A key principle and practice which has emerged from twenty years of responding to HIV/AIDS is that *people living with and affected by HIV/AIDS should be at the centre of the response*. This is referred to as the 'GIPA Principle', i.e. the Greater Involvement of People Living with HIV/AIDS (PLWHA). UNAIDS notes that this term has been widened 'by broad consensus' to include 'people affected by HIV/AIDS', which refers to the HIV-negative partners, children and other family members, and close friends of HIV-positive persons (*From Principle to Practice: Greater Involvement of People Living with or Affected by HIV/AIDS* (GIPA). Geneva: UNAIDS, 1999, p.2). (Note that sometimes 'PLWA' or 'PWHA' may also be used to refer to people living with HIV/AIDS.)

Persons from groups most vulnerable to HIV infection (depending on local contexts), such as young women, persons who inject drugs, men who have sex with men, and prisoners, should also contribute to the design and implementation of programs that affect them.

Because people living with HIV/AIDS, and people from groups most affected, are often financially and socially disadvantaged, they may not be immediately able to participate effectively in consultative forums such as National AIDS Committees and police-community liaison committees. It is therefore not sufficient to ensure representation at the forum. In many cases a capacity building component will need to be included to ensure meaningful participation in consultative mechanisms and decision-making bodies.

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Table 1 sets out the possible levels of involvement by people living with HIV/AIDS and vulnerable groups. The top of the pyramid represents maximum involvement, and support will usually be required to move up the pyramid. *Program staff should ensure that structures exist to permit the participation of people living with HIV/AIDS and vulnerable groups in program design, implementation and evaluation, and consider what capacity building and support may be needed to ensure these opportunities are utilized.*

Table 1: Pyramid of involvement

DECISION MAKERS: PWHAs
and vulnerable groups participate
in decision-making or policy-making
bodies, and their inputs are valued equally
with all the other members of these bodies.

EXPERTS: PWHAs and vulnerable
groups are recognized as important
sources of information, knowledge and skills who
participate – on the same level as professionals –
in design, adaptation and evaluation of interventions.

IMPLEMENTERS: PWHAs
and vulnerable groups carry out
real but instrumental roles in interventions,
e.g. as carers, peer educators or outreach workers.
However, they do not design the intervention or have little
say in how it is run.

SPEAKERS: PWHAs and vulnerable groups are used
as spokespersons in campaigns to change behaviours, or
are brought into conferences or meetings to "share their views"
but otherwise do not participate. (This is often perceived as "token" participation,
where the organizers are conscious of the need to be seen as involving PWHAs and
vulnerable groups, but do not give them any real power or responsibility.)

CONTRIBUTORS: activities involve PWHAs and vulnerable groups
only marginally, generally when the PWHA is already well-known.
For example, using an HIV-positive pop star on a poster, or having relatives
of someone who has recently died of AIDS speak about that person at public occasions.

TARGET AUDIENCES: activities are aimed at or conducted for PWHAs and vulnerable groups, or address them *en masse* rather than as individuals. However, they should be recognized as more than (a) anonymous images on leaflets, posters, or in information, education and communication (IEC) campaigns, (b) people who only receive services, or (c) as "patients" at this level. They can provide important feedback which in turn can influence or inform the sources of the information.

Adapted from *From Principle to Practice: Greater Involvement of People Living with or Affected by HIV/AIDS* (GIPA) (Geneva: UNAIDS, 1999).

Example: Inclusion of people living with HIV/AIDS in program development:
In June 2002 with funding from CIDA and USAID, CARICOM held a regional workshop to develop an action plan for the implementation of the Caribbean Regional Strategic Framework on HIV/AIDS, 2002-2006. People living with HIV/AIDS, including representatives of the Caribbean Network of People Living with HIV/AIDS (CRN+), were invited to the meeting, provided financial support to attend, and time was allocated in the agenda for the presentation and discussion of this perspective. One outcome of the workshop was a 'Checklist of Guiding Principles for Regional Action on HIV/AIDS in the Caribbean' which includes the principle of the meaningful participation of people living with HIV/AIDS as well as vulnerable and affected communities. *Program staff should support the participation of people living with HIV/AIDS and persons from vulnerable groups in programme design, implementation and evaluation. It is generally better to work with persons nominated by local civil society organizations rather than unaffiliated individuals.*

Example: Global Fund for AIDS, Tuberculosis and Malaria
In 2002 a new funding mechanism for national and regional activities, the Global Fund for AIDS, Tuberculosis and Malaria (GFATM), was created. The Global Fund requires that funding proposals be endorsed by a Country Coordinating Mechanism (CCM). CCMs are country-level partnerships that develop and submit grant proposals to the Global Fund, monitor their implementation and coordinate with other donors and domestic programs. CCMs are intended to be multi-sectoral, involving broad representation from government agencies, NGOs, community- and faith-based organizations, private sector institutions, individuals living with HIV, TB or malaria, and bilateral and multilateral agencies. The Board of the GFATM has seats dedicated for civil society representatives and representatives of people living with HIV/AIDS, tuberculosis and malaria. *Program staff should be aware of existing mechanisms for civil society consultation when seeking input on program design, implementation and evaluation.*

Non-discrimination and equality

Discrimination leads to fear, denial, apathy, and isolation. By hindering the participation of people who are infected and affected, discrimination impedes public health prevention and care efforts. The State is responsible for enacting and enforcing laws against discrimination, and also for reducing fear, ignorance, and discrimination by funding public education campaigns, and by other means such as peer-based education.

Non-discrimination is key to meaningful inclusion and participation. HIV-related stigma and discrimination both contribute to and result from social exclusion and marginalization, creating a cycle of increasing alienation which makes meaningful participation difficult if not impossible. Further, persons living with HIV/AIDS from populations which already face discrimination (e.g. women, men who have sex with men, and people who inject drugs) may suffer double discrimination. In order to be effective, HIV/AIDS programming must anticipate and reverse this cycle by supporting people infected and affected to redefine their role in the response to the HIV/AIDS pandemic. *Program staff can ensure programs anticipate and respond appropriately to*

discrimination based on HIV or other status. As noted above, capacity building may be necessary to ensure meaningful inclusion and participation. (See *Stigma and Discrimination: a Conceptual Framework and Basis for Action* (Geneva: UNAIDS, 2002))

Example: Kenyan Network on Ethics, Law and HIV

The Kenyan Network on Ethics, Law and HIV (KELIN) is an incorporated association of lawyers, people living with HIV/AIDS and others which aims to address the legal, ethical and human rights challenges of the HIV/AIDS epidemic in Kenya. In 2001 the Government of Kenya created a national task force on legal issues relating to HIV/AIDS, and after extensive national consultations tabled the AIDS Prevention and Control Bill, which includes the prohibition of discrimination based on HIV status. In 2002 with funding from the Canadian Partnership Branch, the Canadian HIV/AIDS Legal Network initiated a partnership to provide KELIN with financial and technical assistance. This support has assisted KELIN to hold workshops to increase understanding and support for the Bill, which should pass into law in 2004. *Program staff can support law reform to prohibit HIV/AIDS-related discrimination through community education.*

Accountability and transparency

Under international human rights law States are accountable for the protection and promotion of the rights of all the people under their jurisdiction. Accountability may be promoted through the periodic electoral process, or through other mechanisms (particularly important for children, who are outside the electoral process). *Program staff can link HIV/AIDS programs with development programming aimed at improving democracy, governance and participation at national and local levels, according to the national and local context. It is also important to build the capacity of those responsible for respecting, protecting and fulfilling rights to meet accountability benchmarks.*

Accountability requires transparency of decision-making and action. States must make information about the national response to HIV/AIDS, such as national AIDS data, plans and budgets, available for public scrutiny. States should also publish their reports on the implementation of the UNGASS Declaration of Commitment as well as the periodic reports to the human rights treaty committees. States must also respect the rights of freedom of expression and association of civil society to review and disseminate information. *Program staff can strengthen mechanisms of accountability, e.g. through support for national human rights institutions to undertake HIV/AIDS-related education and respond to complaints from people living with HIV/AIDS and vulnerable groups. Support can also be provided to assist States comply with international reporting obligations and build the capacity of States to fulfill their other human rights obligations.*

Indivisibility and interdependence

All human rights are universal, indivisible, interdependent and interrelated. Effective programming may require a greater focus on a particular area in a local context, however care must be taken to ensure all rights are respected in development programming. *Program staff should consider the civil, political, economic, social and cultural aspects of programming on HIV/AIDS.*

Example: Informed consent and mother-to-child transmission

Cheap and effective drug interventions can limit HIV transmission from HIV positive mothers to their children at birth. Routine ('opt-out') testing of all pregnant women has been recommended to identify those who could benefit from this intervention. Yet for many HIV positive women in resource poor settings, this may be the first time they learn of their HIV status, and may have serious family and broader social consequences. HIV testing should only be undertaken with the counselling and informed consent of the women involved, and hence practical protocols for providing counselling and assuring informed consent must be developed which respect the right to privacy (including physical privacy, and confidentiality regarding HIV information) and are also feasible in resource limited settings. Measures for protection of HIV-positive women and girls from abuse should accompany HIV testing programs, and include emergency help-lines, safe shelters for battered women, and training of police and social service providers on AIDS-related violence against women. Other measures include effective prosecution of perpetrators of sexual violence, reform of legislation to criminalize marital rape, and school-based awareness programs for girls and boys. (*Just die quietly: domestic violence and women's vulnerability to HIV in Uganda* (New York: Human Rights Watch, 2003))

Example: children and HIV testing

While there are advantages for the child in knowing his or her HIV status, testing should not be carried out without pre and post-test counselling which is appropriate for the child's individual level of development and emotional maturity. The Southern African AIDS Trust has produced counselling guidelines which respect the rights of children to voice their opinions about issues that affect their lives, and to information and support to help them understand their situation and be involved in making decisions about what is best for them. (*Guidelines for counselling children who are infected with HIV or affected by HIV and AIDS* HIV Counselling Series No.7 (CIDA/CPHA, 2003))

The above two examples demonstrate the indivisibility of human rights in that the right to health, for example, cannot be separated from the right to privacy and the rights of children to express views on matters affecting them

Example: Recommendations to the donor community for HIV/AIDS programming for girls in Zambia

In 2002 Human Rights Watch published an analysis of the causes and impact of HIV/AIDS on girls in Zambia. The report contains the elements of a human rights situation and response analysis for Zambia in this area, and includes recommendations to the Government of Zambia and the United Nations system, as well as the following specific recommendations to the donor community:

- Assist in the development of governmental and nongovernmental programs designed to address the link between sexual violence and coercion and HIV/AIDS in Zambia.
- Target support at programs to enhance protection of girls' rights and to develop mechanisms to monitor these abuses.
- Provide financial and technical assistance to civil society organizations that seek to address abuses against girls, including legal services, counselling and testing, and medical assistance.
- Contribute to training law enforcement and judicial personnel on the links between sexual violence and HIV/AIDS, and on international legal standards.
- Assist law enforcement agencies in acquiring necessary forensic skills and equipment for investigating cases of sexual violence.
- Engage publicly and privately with the Zambian government to highlight the importance of including violence against girls and women in broader AIDS prevention programs.
- Ensure that the specific needs of girls at risk of HIV infection are addressed.

(Suffering in silence: the links between human rights abuses and HIV transmission to girls in Zambia (New York: Human Rights Watch, 2002))

3.   Program design, implementation and evaluation

Gender analysis and integration

Good practice, policy and international legal imperatives require the mainstreaming of gender equality in human rights programming on HIV/AIDS. This process should be participatory and non-discriminatory, transparent, and accountable. Issues of confidentiality and privacy are particularly important as women's autonomy is often not respected in matters of sexual and reproductive health. Violence against women and girls, including sexual assault, carry the additional threat of HIV infection and are central human rights concerns. Sex-disaggregated data and a gender based analysis are necessary to understand the local epidemic, identify double discrimination (i.e. on the grounds of both HIV status and gender), and propose responses that meet the different needs of girls and boys, women and men. (See generally UNIFEM's web portal Gender and HIV/AIDS www.genderandaids.org)

Example: Negative impact of laws criminalizing sexual transmission of HIV

In some sub-Saharan African countries many young women living with HIV were infected by much older male partners. Several governments have proposed laws to criminalize the knowing spread of HIV infection in order to protect young women. However such laws may deter people from seeking voluntary HIV testing and counselling, and they may also impact more negatively on young women who first learn of their HIV status through antenatal screening for HIV. These women may be accused of 'bringing HIV into the family', and face violence and rejection. *Program staff should undertake a gender analysis of programme design to ensure results benefit both men and women.* (See *Criminal law, public health and HIV transmission: a policy options paper* (Geneva, UNAIDS, 2002))

Example: Voices of HIV positive women

In 2001 a series of consultations were held across Kenya on HIV/AIDS-related law reform. At one public meeting in Nairobi about sixty persons participated, many of them from the legal profession. All of the participants who spoke openly about their HIV positive status were women. In sub-Saharan Africa both national and regional women's organizations, such as the Society for Women and AIDS in Africa (SWAA), and FIDA (Federation of Women Lawyers), are responding to HIV/AIDS. *Program staff should consult women's organizations when developing human rights programs on HIV/AIDS.* (See CIDA's *Policy on Gender Equality (1999)).* (Note that this example also illustrates the principle of participation.)

Leverage – doing more with less

Because HIV/AIDS programs often address socially stigmatized behaviour and vulnerable and disadvantaged groups, some donors have shied away from supporting interventions which have nonetheless demonstrated success in reducing the spread and impact of HIV infection and AIDS. Although Canada's financial contribution may be smaller in absolute terms, strategic program design, including addressing key areas overlooked by other donors, can achieve a significantly greater impact. Sensitive areas include programs addressing the needs of sexually-active children, injecting drug users, men who have sex with men, and commercial sex workers.

Example: Canada's support for the inclusion of people living with HIV/AIDS and vulnerable groups at the UNGASS on HIV/AIDS

In September 2001, Canada championed the participation of people living with HIV/AIDS in the United Nations General Assembly Special Session (UNGASS) on HIV/AIDS. Canada included a person living with HIV/AIDS on its official delegation, and also supported the inclusion of a representative from the International Gay and Lesbian Human Rights Commission in an official round table discussion. This public stand on the inclusion of PLWHAs and representatives of affected communities was a highly visible and significant statement of the importance of meaningful participation and inclusion in the global response to HIV/AIDS. *The participation of representatives of disadvantaged and stigmatized groups should be supported, particularly in forums where these voices would not otherwise be heard.* (This example also illustrates the principle of participation.)

Indicators

HIV/AIDS is a highly stigmatized condition and indicators for human rights programming on HIV/AIDS should be developed sensitively in order to measure the extent to which the rights of people living with HIV/AIDS and vulnerable groups are respected, protected and fulfilled. This may be made difficult by the stigmatization and discrimination faced by these groups. Data disaggregation may be required not only by gender but by HIV status, drug use, sexual orientation, and age. This may cause problems, particularly in small rural communities.

The following examples demonstrate the importance of disaggregated data, the use of national indicators to measure HIV/AIDS structures, laws and policies that reflect human rights approaches, and indicators developed for a small project to develop the capacity of a civil society organization using human rights approaches in Zambia.

Example: Children's rights to education in Kenya
In recent years the official number of young children attending school in Kenya has increased substantially following a government commitment to ensure primary education for all children. Yet in 2003 these figures did not reveal that children suspected of being HIV-positive (including those from a Nairobi orphanage for AIDS-affected children) were systematically refused admission to government schools. Following legal action, in 2004 the Kenyan government directed its schools to admit children irrespective of their HIV status. *Program staff should ensure that data is disaggregated to reveal any HIV/AIDS-related discrimination – confidentiality should also be assured.* (This example also illustrates the principle of transparency.)

Example: UNAIDS core indicators for the implementation of the Declaration of Commitment – national commitment and action
UNAIDS has developed core indicators for monitoring national implementation of the Declaration of Commitment on HIV/AIDS. Every UN Member State endorsed the Declaration and is requested to submit periodic reports on its implementation, which are posted on the UNAIDS web site. The National Composite Policy Index Questionnaire is used to measure government HIV/AIDS policies for the reports, and includes the following indicators:
*   *Country has a functional national body that promotes interaction among government, the private sector and civil society.*
*   *Country has a functional national body that assists in the coordination of civil society organizations.*
*   *Country has laws and regulations that protect against discrimination of people living with HIV/AIDS.*
*   *Country has laws and regulations that protect against discrimination of people identified as being especially vulnerable to HIV/AIDS.*
*   *Country has a policy or strategy to ensure or improve access to HIV/AIDS-related medicines, with emphasis on vulnerable groups…*

Program staff can use these indicators to evaluate individual country progress in developing the necessary legislative framework and design programs accordingly. Regional and 'South-South' programs can identify regional strengths, weaknesses, and opportunities for collaboration. (Monitoring the Declaration of Commitment on HIV/AIDS: Guidelines on Construction of Core Indicators (UNAIDS, 2002))

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Example: Capacity-building project, Zambia

The goal of this project is to enhance the response to HIV/AIDS in Zambia through the strengthening of a national association of lawyers to address priority legal, ethical and human rights issues. (Project supported by CIDA's Canadian Partnership Branch – see Canadian HIV/AIDS Legal Network web site: 'Promoting a rights-based approach to HIV/AIDS internationally' www.aidslaw.ca/Maincontent/issues/discrimination/rights_approach/international.htm)

Outputs	Output indicators
1.1 Increased capacity of organization to address HIV/AIDS-related legal, ethical and human rights issues.	1.1.1 Strategic plan for 2004-2006 developed 1.1.2 # of reports on priority issues published 1.1.3 range of distribution (organization. professionals) 1.1.4 # of workshops & seminars 1.1.5 attendance - #, gender representation, range of organizations & professions 1.1.6 additional resources leveraged
2.1 Exchange of information and experience with other organizations in Zambia working on related issues;	2.1.1 # of forums attended, submissions made 2.1.2 # of joint activities undertaken
2.2 Establishment/ strengthening of mechanisms for government-civil society collaboration on HIV/AIDS law and policy.	2.2.1 links with national AIDS programme, government ministries established and active
2.3 Increased participation in mechanisms for dialogue with national AIDS programme, government ministries on legal and policy issues	2.3.1 # of opportunities for dialogue with national AIDS programme, government ministries 2.3.2 feedback from key stakeholders on level of participation and effectiveness
3.1 Exchange of information and experience between organizations regionally and internationally undertaking similar work	3.1.1 Email and web access established. 3.1.2 # articles in resource centre 3.1.3 # of conferences attended and presentations made 3.1.4 # of regional study tours, exchanges undertaken 3.1.5 participants' profile (men/ women, professions/ organizations)
3.2 Partners have improved capacity to contribute to international dialogue on HIV/AIDS related legal and policy issues	3.2.1 Partner organization's level of participation in regional/ international events 3.2.2 Feedback from other stakeholders on partners' contribution.
Outcomes	**Outcome indicators**
Enhanced capacity of organizations and members to respond to legal and policy issues related to HIV/AIDS	1. Change in organization's membership over life of project (gender disaggregated data) 2. # and range of interventions related to HIV/AIDS legal and policy issues 3. # and range of national networks in which partner organizations are involved 4. level and nature of engagement with other organizations regionally and internationally 5. policy changes related to HIV/AIDS
Short term impact	**Impact indicators**
Measures to achieve law and policy reform aimed at reducing the spread and impact of HIV/AIDS.	1. #, range of new groups that have become engaged through partner activities 2. policy changes related to HIV/AIDS 3. increased funding for HIV/AIDS related programming

Program staff should be wary of identifying legislation alone as a measure of the protection and promotion of human rights relating to HIV/AIDS. While appropriate legislation is essential, many other factors also determine the impact of legislative measures. Legislative reform may take 5-15 years. Other indicators, such as those measuring the development of civil society capacity to engage with government on key issues, may be more useful in evaluating programme outcomes and impact.

Results: Outputs, Outcomes and Impact

Results-based management tools focus on outputs, outcomes and impacts. Yet as noted above outcomes such as law reform may be beyond the program time frame and subject to multiple risks outside the control of the program design. Law reform itself is no indication that rights are respected and protected. Formal and informal policies and practices are more amenable to change in the shorter term, although informal policies and practices may be more difficult to identify and measure. Enhanced capacity of civil society to hold governments accountable for protecting and promoting human rights in the context of HIV/AIDS is an essential component of human rights approaches to HIV/AIDS.

Example: Regional Project on HIV/AIDS, Law, Ethics and Human Rights
The following results chain is drawn from a 5-year Caribbean regional HIV/AIDS project. The project goal is to support the Caribbean regional plan to reduce the spread and impact of HIV/AIDS. The project purpose is to strengthen the capacity of regional organizations (governmental and non-governmental) to respond effectively to HIV/AIDS in the Caribbean. (Project supported by CIDA's 'Enhanced Support to HIV/AIDS in the Caribbean (ESAC)' Program – see Canadian HIV/AIDS Legal Network web site: 'Promoting a rights-based approach to HIV/AIDS internationally' www.aidslaw.ca/Maincontent/issues/discrimination/rights_approach/international.htm)

Inputs: Financial and technical resources, including legal, project planning and management, research and facilitation skills.

Activities: Training, technical assistance, seminars, workshops, materials development, networking coaching, diagnostic work.

Outputs:
- *Advocacy* – increased capacity of regional organizations to inform policy makers of impact of HIV/AIDS epidemic and to promote adoption of human rights and non-discriminatory policies and practices.
- *Service delivery* – increased capacity in regional organizations to provide quality services and technical assistance for HIV/AIDS prevention and control and PLWHA care.
- *Program management* – increased capacity in regional organizations to analyze, design, implement and monitor their programming.
- *Strategic coordination* – increased capacity in regional organizations to exchange information, coordinate initiatives and form effective strategic alliances.

Outcomes:
- *Policy and Legal Framework* – Effective policy and legislation dealing with HIV/AIDS

- *PLWHA Care and Support* – Appropriate care and support for people living with HIV/AIDS
- *HIV Prevention* – Reduced transmission among vulnerable groups, including young people
- *HIV Prevention* – Reduced transmission from mother to child.

Impact:
- Decrease in the incidence of HIV/AIDS in selected countries in the Caribbean.
- Increased quality of life for people living with HIV/AIDS and their families.

Outcome performance indicators:
- National government allocations for HIV/AIDS programs
- Number of countries with new policies and laws to protect the rights of PLWHAs.
- Number of countries with effective mechanisms for policy enforcement.

Reporting

The principle of accountability and transparency requires that results should be reported back to the persons and communities which participated in the data collection process (while protecting confidentiality and program integrity). Program staff should be aware that data may be used for other national reporting processes, such as shadow reports to the international human rights treaty bodies. Stakeholder clarity and agreement at commencement regarding the use of data collected will help avoid later conflict. In all cases reports should protect the confidentiality of people living with HIV/AIDS and affected communities.

Example: community stigmatized by HIV sero-prevalence survey
In Ghana in the 1990s an anonymous HIV sero-prevalence survey reported a high HIV prevalence among persons from an eastern region of the country. This was followed by reports of stigmatization and discrimination against persons from this region. The sentinel testing was undertaken without consent, counselling or individual notification of results. How could the data necessary to develop an appropriate HIV/AIDS program have been obtained without stigmatizing part of the population in this way?

Assumptions and risks

Program staff should be sensitive to their own potential prejudices and those of their colleagues when designing and evaluating HIV/AIDS programs. In particular it should not be assumed that all program staff are comfortable working as equals with people living with HIV/AIDS and members of vulnerable groups. In-house sensitization training should be considered, using a facilitator skilled in working with issues such as stereotyping and homophobia.

The implementing agency must also have an adequate workplace policy on HIV/AIDS. The model policy developed by the International Labour Organization is a useful benchmark for evaluating institutional capacity in this area. (See *Code of Practice on HIV/AIDS and the World of Work* (Geneva: ILO, 2001)).

Programming HIV/AIDS: a human rights approach

The following table sets out some of the risks which might arise in the design and implementation of HIV/AIDS programs using human rights approaches, and steps which can be taken to reduce these risks:

Risks	Remedies
Governments and decision makers may be uncomfortable with the 'non-traditional expertise' possessed by persons living with HIV/AIDS and persons from vulnerable communities. Difficulties may arise in having these voices acknowledged in program design and implementation (principle of participation and inclusion)	• Capacity building to increase community representative advocacy skills • Identification and training of advocates who can articulate the needs and interests of the vulnerable communities • Encourage strategic alliances with advocacy groups working in related areas
Higher turnover of project personnel may occur, both for health reasons and because qualified persons with HIV/AIDS and development experience are often difficult to recruit and retain (right to health and non-discrimination in the workplace.) Civil society organizations responding to HIV/AIDS, particularly PLWHA groups and organizations of people most vulnerable, may be weak and require substantial capacity development.	• International development organizations are increasingly recognising the need to identify treatment options, and to allow the costs of staff treatment and care in program budgets. • Take extra care to ensure the continuity of civil society partner institutional memory, organizational succession planning, and inclusive management styles that share responsibilities, information and access.
In some contexts, proposed program activities may be technically illegal or highly stigmatized, particularly when working with disadvantaged populations (street children and youth, commercial sex workers, drug users, men who have sex with men). For example, project staff providing health information and condoms or clean needles and syringes may fear being charged with 'aiding and abetting' illegal activities (right to privacy and non-discrimination). Nongovernmental organizations of vulnerable groups (such gay men, drug users or commercial sex workers) may be refused official registration and hence access to funding on the grounds that they are promoting immoral or illegal activities (rights of freedom of expression and association).	• Promote stakeholder commitment to outcomes by inclusion in program design and implementation. • Include human rights and other groups with relevant experience in project design and implementation. • Collect evidence of successful interventions in similar cultural and legal contexts. • Engage with local authorities and opinion leaders; identify and recruit 'champions.' • Work with the media to avoid negative and inflammatory reports. • Seek legal advice to ascertain facts and practice (some activities may be wrongly assumed to be illegal, in other cases authorities may be convinced to 'turn a blind eye' on public health grounds.) • Check government statements and commitments at international forums, and in international law.

Program integration with national, regional and international development, HIV/AIDS, and human rights frameworks

National Frameworks

Poverty Reduction Strategy Papers (PRSP)

Human rights approaches require that people living with HIV/AIDS and vulnerable groups be fully engaged in the development of national strategies and frameworks. In those countries that prepare PRSPs this means ensuring that representatives of affected communities are supported to participate in national consultations, that the PRSPs reflect their perspectives and address their concerns, and that the results of the consultations are reported back to the communities concerned, consistent with best practice for participatory processes in stakeholder consultations.

National Strategic Plans on HIV/AIDS

Most countries have undertaken situation and response analyses and have prepared a national strategic or medium term plan on HIV/AIDS (often of three to five years in duration) – some countries will be implementing their second or even third such plan. HIV/AIDS programming should be directed towards supporting the implementation of these plans. National AIDS plans are generally not explicitly rights-based however, and may be deficient in some aspects. Programs should be developed in collaboration with the national AIDS program to address gaps, avoid duplication of activities, and promote the sharing of information and best practices.

When reviewing national plans, program staff should ensure that they reflect human rights principles and that the plans:

Participation and inclusion
- *have been prepared with adequate community consultation,*

Non-discrimination and equality
- *are based on reliable epidemiological data, particularly regarding groups most vulnerable to HIV infection,*
- *adequately address the particular needs of one or more vulnerable populations (e.g. young women and girls, prisoners, injecting drug users, street children and youth, men who have sex with men),*

Accountability and transparency
- *situate the national response within an international human rights legal and policy context,*

Indivisibility and interdependence
- *adequately address the need for an enabling legal and policy environment, and*
- *adequately identify and propose measures to address the underlying determinants of infection and impact, such as poverty, stigma and discrimination.*

National human rights action plans

Some countries have already developed, or may be developing, national human rights action plans which may make reference to HIV/AIDS. Countries which have developed national plans include Bolivia, Brazil (refers specifically to HIV/AIDS), Ecuador, Indonesia, Latvia, Lithuania, Malawi, Mexico, the Philippines, South Africa and Venezuela. These plans provide an opportunity to link HIV/AIDS programming with other initiatives to address human rights concerns which contribute to HIV/AIDS spread and impact.

Regional legal frameworks

Regional human rights frameworks exist in Europe, Africa and the Americas. The African Charter on Human and People's Rights takes an integrated approach to civil, political, economic, social and cultural rights and recognizes the centrality of the family and the community. The Inter-American system has already been used to assure access to treatments for people living with HIV/AIDS (*Report on access to comprehensive care, anti-retroviral treatment (ARVs) and human rights of people living with HIV/AIDS in Latin America and the Caribbean* Submission to the Inter-American Commission on Human Rights (LACCASO / Agua Buena / Center for Justice and International Law, 2002)). Support for such interventions has the additional advantage of promoting the rule of law, and awareness and use of these mechanisms.

International legal frameworks

Reports on human rights provide an opportunity to hold governments accountable for action on HIV/AIDS, and for civil society to engage with government on its performance. The process of developing the reports, and the civil society consultations before and after the reports have been developed, can provide significant opportunities for reviewing national performance in meeting agreed international goals.

National reports to human rights treaty bodies

Governments have legal obligations to report periodically on measures taken to respect, protect and fulfil the rights set out in the international legal conventions and treaties. 'Shadow reports' from civil society organizations will also be accepted. These reports are reviewed by independent committees of experts, which then publish commentaries on aspects of the reports. The process provides an opportunity to build local capacity to advocate for responses to HIV/AIDS which respect human rights, encourage government-civil society dialogue on HIV/AIDS policy and programs, and promote the rule of law. Occasionally the treaty body committees will issue General Comments, which are authoritative interpretations of State obligations in particular areas. *Program staff can refer to these observations and recommendations when designing programs, when reviewing proposals, and when monitoring the implementation of programs.*

Example: The right to health and child and adolescent sensitive health services
All but two UN Member States (the USA and Somalia) have ratified or acceded to the Convention on the Rights of the Child. The Committee on the Rights of the Child (CRC), which monitors the implementation of the Convention, has issued recommendations for States when responding to HIV/AIDS, and will examine State periodic reports with these points in mind. With respect to health services, the Committee notes that children are more likely to use services that are friendly and supportive, provide a wide range of services and information, are geared to their needs, give them the opportunity to participate in decisions affecting their health, are accessible, affordable, confidential and non-judgmental, do not require parental consent and are not discriminatory. Taking into account the evolving capacities of the child, the Committee urged States to ensure that health services employ trained personnel who fully respect the rights of the child to privacy and non-discrimination in access to HIV-related information, voluntary counselling and testing, knowledge of their HIV status, confidential sexual and reproductive health services, and free or low-cost contraceptive methods and services. (*HIV/AIDS and the Rights of the Child* General Comment No. 3, Committee on the Rights of the Child, 2003)

National reports on the UNGASS Declaration of Commitment

All countries are requested to report annually on measures taken to meet their commitment to implementing the UNGASS Declaration of Commitment. UNAIDS has developed a set of core indicators (noted above), which includes a national composite policy index. This index includes specific questions on laws and regulations that protect against discrimination people living with HIV/AIDS and people identified as being especially vulnerable to HIV/AIDS.

National reports to the Commission on Human Rights

The Commission on Human Rights addresses HIV/AIDS at its annual sessions, and has adopted resolutions calling on States to report voluntarily on measures taken to address aspects of the epidemic, such as access to treatment, and human rights protection and promotion. The Commission has requested States to report on measures taken, where appropriate, to promote and implement the International Guidelines on HIV/AIDS and Human Rights. These country reports are then compiled and considered by the Commission at the next session. This provides a further opportunity to measure compliance with the International Guidelines and to publish and share good practices.

4. Checklists for reviewing proposals and programs

These checklists apply human rights principles to program design, monitoring and evaluation in the context of HIV/AIDS.

Checklist for reviewing new proposals

- **participation and inclusion**
  - o Was there meaningful participation of key stakeholder groups (including women, children, people living with HIV/AIDS and vulnerable communities) in the situation analysis and consultations on program design? (Refer to the Pyramid of Involvement in Table 1.)
  - o Do the proposed program monitoring mechanisms include adequate representation of women, children, people living with HIV/AIDS and vulnerable communities? Are these persons adequately supported to ensure their participation is meaningful?
- **non-discrimination and equality**
  - o Does the implementing organization have an adequate policy on HIV in the workplace?
  - o Are privacy and confidentiality appropriately respected and protected?
  - o Does the situation analysis include data disaggregated by sex, age, and other factors, as appropriate?
  - o Does the program design promote non-discrimination and equality for all beneficiaries?
  - o Does the program promote gender equality?
  - o Will women and children (both girls and boys) benefit directly from the program?
  - o Does the program complement other national activities so as to ensure all disadvantaged groups are reached?
- **accountability and transparency**
  - o Does the program promote government accountability for respecting and promoting human rights relevant to HIV/AIDS?
  - o Does the program include accountability mechanisms so beneficiaries and other stakeholders can monitor program implementation?
  - o Is relevant program documentation available and accessible in national languages? Are the needs of persons with limited literacy addressed?
- **indivisibility and interdependence**
  - o Does the program treat all rights as equal? If rights are to be limited, do these restrictions satisfy the Siracusa Principles?
  - o Does the program appropriately distinguish rights of immediate application and rights which may be implemented progressively?
  - o Does the program balance short term and longer term goals, such as service provision, education, and law and policy reform?
  - o Does the program complement activities to respect, protect and fulfill rights in other areas?

Checklist for program monitoring and mid-term review

- **participation and inclusion**
  - o Do the program monitoring mechanisms include adequate representation of women, people living with HIV/AIDS and vulnerable communities? Are these persons adequately supported to ensure their participation is meaningful?
- **non-discrimination and equality**
  - o Does the program implementation respect non-discrimination and equality?
  - o Are women and children (both girls and boys) engaged and benefiting as anticipated in the program design?
  - o Does the program implementation reveal groups whose needs are not being met by the program design?
- **accountability and transparency**
  - o Will the review promote government accountability for respecting and promoting human rights related to HIV/AIDS?
  - o Will the results of the review be reported back to beneficiaries and other stakeholders in ways that are meaningful for them?
  - o Is relevant program documentation available and accessible in national languages? Are the needs of persons with limited literacy addressed?
- **indivisibility and interdependence**
  - o Does the program treat all rights as equal? If some rights are limited by the program activities, do these restrictions satisfy the Siracusa Principles?
  - o Does the program balance short term and longer term goals, such as service provision, education, and law and policy reform?
  - o Does the program complement activities respect protect and fulfill rights in other areas?

Checklist for program evaluation

- **participation and inclusion**
  - o Is there meaningful participation of key stakeholder groups (including women, people living with HIV/AIDS and vulnerable communities) in the program evaluation mechanisms and processes? Are these persons adequately supported to ensure their participation is meaningful?
- **non-discrimination and equality**
  - o Did the program design promote non-discrimination and equality for all beneficiaries?
  - o Did women and children (both girls and boys) benefit directly from the program?
  - o Did the program complement other national activities so as to ensure all disadvantaged groups were reached?
- **accountability and transparency**
  - o Did the program promote government accountability for respecting and promoting human rights related to HIV/AIDS?
  - o Did the program include accountability mechanisms so beneficiaries and other stakeholders could monitor program implementation?

- o Was relevant program documentation available and accessible in national languages? Were the needs of persons with limited literacy addressed? (also relevant for non-discrimination)
- **indivisibility and interdependence**
  - o Did the program treat all rights as equal? If rights were limited by the program activities, did these restrictions satisfy the Siracusa Principles?
  - o Did the program appropriately distinguish rights of immediate application and rights which may be implemented progressively?
  - o Did the program balance short term and longer term human rights goals, such as service provision, education, and law and policy reform?
  - o Did the program complement activities to respect protect and fulfill rights in other areas?

5. Lessons learned

Rights literacy cannot be assumed

Although the value of human rights approaches in a range of programming areas is being increasingly recognized, there remain a lot of misconceptions about the foundations for, and applications of, human rights approaches and their application to HIV/AIDS. Basic information such as the human rights treaties ratified by a particular country, and due dates for the next periodic reports, are typically not part of the HIV/AIDS situation analysis. Similarly, the progressive nature of certain obligations, the rules providing for legitimate exceptions to human rights protections, and State obligations to protect individuals from harmful activities by other actors, including the private sector, are not well understood. Human rights programming approaches should include a human rights promotion and education component which addresses these issues, as appropriate. Strategic alliances may be built with human rights organizations addressing HIV/AIDS and related areas for this purpose.

Participation requires support and capacity building

People living with HIV/AIDS and communities most vulnerable to HIV/AIDS should be involved in designing, implementing and evaluating HIV/AIDS policies and programs (the 'GIPA principle'). However, it cannot be assumed that 'a place at the table' means that these perspectives will be appropriately articulated and incorporated. Because of the nature of their vulnerability, these groups may be less able to participate in such consultation processes. Reasons may include the lack of a bus fare to attend a consultation, the lack of skills to communicate effectively, or a realistic fear of stigma, violence and discrimination.

HIV/AIDS programs should therefore include measures to ensure effective participation of adults and children. These measures can include financial and technical support to associations of people living with HIV/AIDS, and associations of groups most vulnerable. In some contexts lawyers or other trained advocates have been engaged to advise and represent the disadvantaged living with or affected by HIV/AIDS.

Fragile states may require different approaches

International human rights law situates responsibility for protecting and promoting human rights with national governments. In some States governments are so fragile as to be unable to assure even their core human rights obligations. This lack of capacity may be the result of factors including war, internal conflict and, increasing, HIV/AIDS itself. This presents challenges for development programming, including the need to balance the provision of immediate assistance through non-State actors such as international relief agencies, and the need to strengthen State capacity to assure rights in the longer term. Vulnerability to HIV infection and the impact of HIV/AIDS is increased in such situations, and relief and State-building programs should nonetheless reflect international human rights law and principles. International agencies should also model human rights approaches by ensuring that their local staff are covered by appropriate HIV/AIDS workplace policies.

Much can be learned from regional and international experience

Many countries over-emphasize the specificity of local cultures and practices, and down-play the commonality of experience between countries, even within the same region. The universality and indivisibility of the international human rights framework ('all human rights for all') emphasizes the inalienability of human rights, whatever the culture and context. Multi-country and regional approaches encourage the sharing of relevant experiences. Documentation and dissemination of experiences, study tours, staff exchanges, and information technology such as web publishing and email all offer opportunities for sharing experience.

6.   Good practice examples

The following good practice examples illustrate the application of human rights principles to HIV/AIDS programs. One of the challenges of human rights programming in this area is the need for adequate documentation of good practices and lessons learned.

National approaches

Philippines National AIDS Council

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 included the perspectives of people living with HIV/AIDS and vulnerable groups. A key achievement of the Strategy is the mainstreaming of AIDS information and education in government departments responsible for education and the interior.

AIDS Law Project, South Africa

The AIDS Law Project was founded in 1993 and is based at the Centre for Applied Legal Studies, University of Witwatersrand. The Project:

- carries out litigation to counter wrongs that have occurred and, where possible, to establish legal precedents that prevent them from recurring;
- offers free legal advice that will empower people with HIV and AIDS to seek legal remedies in response to acts of unfair discrimination;
- carries out research to support policy formulation and bring about practices that prevent discrimination; and
- produces media that create an awareness of rights in government and civil society and promote effective lobbying and advocacy.

HIV/AIDS-related legal issues addressed by the AIDS Law Project have included:
- the lawfulness of HIV testing in the workplace;
- rights concerning access to treatments;
- wilful transmission and HIV infection in marriage;
- rights of domestic workers;
- privacy for children with HIV in pre-school, school, and hospital settings;
- treatment for sexually abused women and rape survivors;
- protocols concerning needle-stick injuries;
- liability for infection through blood transfusions;
- adoption; and
- rights to cover HIV infection by means of medical aid schemes.

AIDS Law Project researchers, attorneys, and paralegal officers speak at over 250 meetings a year on a range of topics about AIDS, development, employment, human rights, and the rule of law.

Zambian AIDS Law Research and Advocacy Network

The Zambian AIDS Law Research and Advocacy Network (ZARAN) is an incorporated association of lawyers and students, with close links to the Zambian Network of People living with HIV/AIDS. In 2002 ZARAN commenced a CIDA-funded two year capacity building project with technical assistance from the Canadian HIV/AIDS Legal Network. One focus of activities was a successful advocacy campaign to reverse a government proposal for the exclusion of HIV positive recruits from the Zambian armed forces.

Regional approaches

Southern African AIDS Trust (SAT)

The Southern African AIDS Trust (SAT) is based in Harare, Zimbabwe. SAT is a regional NGO that supports community responses to HIV and AIDS through in-depth partnerships in Malawi, Mozambique, Tanzania, Zambia and Zimbabwe with wider networking, skills exchange and lesson sharing throughout the region. SAT funding, skills building and lesson sharing activities support partners in a wide range of relevant activities such as HIV prevention, care and support, People Living with HIV and AIDS (PLWHA) support groups and networks, impact mitigation, networking and information exchange, HIV-related advocacy on gender and human/child rights. The overall SAT goal is to increase the HIV competence of communities. SAT partners include:
- community-based organizations;

- church-related organizations and mission hospitals;
- women's health and advocacy organizations;
- legal reform and human rights organizations;
- support groups and networks for PLWHA;
- youth groups and programs for street children;
- gay and lesbian groups;
- advocacy and policy organizations;
- national AIDS NGO networks.

Early discussions with SAT partners revealed that they had difficulty in responding to HIV and AIDS-related human rights abuses in their work. Several partners requested assistance to build their skills and capacity in this area, and in response SAT developed a series of workshops that demonstrated the linkage between HIV, gender, human rights, and child rights issues in practical terms. The workshops identified the laws, both national and customary, that could be applied to enhance the lives of PLWHA. Furthermore, SAT partners are equipped with advocacy skills to enable them to lobby for law reform.

A number of partners have since been involved in highly visible landmark cases and initiatives. These include the introduction of the Sexual Offences Act in Tanzania, which was passed to safeguard the rights of women and children against sexual abuse. SAT partners have also played a prominent role in lobbying for land rights for women in Zimbabwe, Tanzania, and Zambia.

To achieve its goal of strengthening community competence, SAT strategic outcomes include linking gender equality, human rights, children's rights and HIV-related issues. All SAT partners must have a demonstrated commitment to social justice, human rights, gender equality and the rights of children. SAT partners are encouraged and supported to link these issues in their advocacy and networking activities. SAT also promotes 'South-South' networking by bringing together activists on gender equality, human rights, community development and AIDS from different countries in southern Africa. www.satregional.org

HIV/AIDS Law, Ethics and Human Rights in the Caribbean

The Caribbean Regional Strategic Framework for HIV/AIDS 2002-2006 lists as the first of six priority areas for action 'advocacy, policy development and legislation.' To implement this priority area, in 2002 CIDA funded the development of an 'Action Plan on Law, Ethics and Human Rights.' This plan was developed through a consultative process including people living with and affected by HIV/AIDS, and supported a subsequent proposal to CIDA for regional project to support the implementation of priority area one of the Regional Strategic Framework in the areas of law, ethics and human rights. www.caricom.org

Sectoral approaches

ILO and the world of work

The International Labour Organization has developed a code of practice on HIV/AIDS in the workplace based on a tripartite (governments, labour, private sector) framework which reflects international human rights law. The ILO also undertakes other activities to promote human rights approaches to HIV/AIDS and the world of work, including training for judges on the workplace implications of HIV/AIDS. For each training event, the ILO contracts papers to be written by national legal practitioners or law faculty staff, drawing on HIV/AIDS-related court cases from the particular region to use as a source of comparative labour law. Examples of good practice are shared, including trends in recent jurisprudence, for example concerning the "inherent requirements of the job" test for attempting to exclude sero-positive applicants, and the relationship between an employer's duty to provide a safe and healthy working environment and the right not to be discriminated against at work. www.ilo.org/public/english/protection/trav/aids/

Documentation

In the Shadow of Death: HIV/AIDS and Children's Rights in Kenya

In 2001 Human Rights Watch published an analysis of the impact of HIV/AIDS on children in Kenya. This report reflects the human rights approach because:

- It situates the issues and the corresponding obligations to respond within Kenya's international legal obligations (including references to the International Guidelines on HIV/AIDS and Human Rights);
- It identifies the present legal framework and administrative structures in Kenya providing for the protection of children;
- It identifies concrete actions for the Government of Kenya and the international community, including e.g. the ratification of an international treaty on child labour and the adoption of legislation addressing issues such as legal assistance for children in property disputes; and
- The evidence on which the report is based includes testimony from AIDS-affected children and young adults or their guardians.

This report could be used as part of a situation and response analysis for the development of a component to address the impact of HIV/AIDS on children in Kenya. *In the shadow of death: HIV/AIDS and children's rights in Kenya* (Human Rights Watch, 2001) www.hrw.org

Other examples

Law reform

- **Nicaragua**: In 1996, the UNDP hosted a parliamentary seminar on HIV/AIDS. A law to protect rights in the context of AIDS was subsequently enacted. A communications strategy was developed, using a video to illustrate the ethical and human rights aspects of the law.

- **Kenya**: In 2002 the Task Force on Legal Issues relating to HIV/AIDS, convened by the Attorney-General to report on recommendations for HIV/AIDS–related law reform, finished an extensive series of national consultations and submitted its report. A Bill was drafted based on these recommendations and should become law in 2004.

Legal advice and litigation

- **India:** The Lawyers Collective HIV/AIDS Unit responds specifically to the legal needs of people with HIV/AIDS. The Unit provides legal aid and advice, promotes awareness of HIV-related legal issues in the general community and among the legal profession, and advocates for law reform.
- **Costa Rica:** As a result of legal action by the Coalition of Costa Ricans with HIV/AIDS, the Supreme Court ruled that the national health-care system should provide certain medications for people with HIV infection.

Human rights education

- **South Africa**: The AIDS Law Project and Lawyers for Human Rights have published a resource manual in plain English for people with HIV/AIDS and the general community which sets out the rights of different stakeholders in situations of potential conflict, and redress available under South African law.

Monitoring and documentation

- **Burma & Thailand**: Human Rights Watch investigated the trafficking of girls and their vulnerability to HIV infection. The report reconceptualized the issue as a "human rights violation" rather than a "social problem."
- **Romania**: The Bucharest Acceptance Group was funded by UNAIDS to report on the impact of the criminal law on HIV/AIDS prevention among men who have sex with men. The United Nations Human Rights Committee considered the report and other evidence, and recommended that Romania reform its laws on homosexual relations between consenting adults.

Women's rights

- **India**: The Lawyers Collective applied a gender analysis and identified a number of laws whose impact increased the vulnerability of women to HIV and AIDS. Advocacy for appropriate law reform has resulted.
- **Zimbabwe**: Groups such as the Women and AIDS Support Network applied a gender analysis to a proposal to increase criminal penalties for HIV transmission and realized that, for complex social reasons, women would be differentially affected. These groups then lobbied for a different approach based on a gender and rights analysis.

Children's rights

- **Malawi:** To address the issue of children orphaned by HIV/AIDS within the framework of the Convention on the Rights of the Child, community-based organizations are using a training manual developed by the Unit for Research and Education on the Convention on the Rights of the Child, University of Victoria, Canada.

- **Zimbabwe**: The Victim Friendly Court System is a multidisciplinary initiative in which the legal courts in Zimbabwe that deal with cases of child sexual abuse rely on evidence provided by a team of experts - such as doctors, psychologists, and social workers - that attends to the victims of child sexual abuse. The children's hearings take place in camera and they do not have to face the perpetrators. The Family Support Trust coordinates treatment, counselling, and support for the children who have been abused.

7.　Resources and information

Publications

25 Questions and Answers on Health and Human Rights (Geneva: WHO, 2002) www.who.int/hhr/activities/publications/en/

Action Guide for United Nations Country Teams: Implementing the Declaration of Commitment on HIV/AIDS (Geneva: UNAIDS, 2002) www.unaids.org

AIDS epidemic update (Geneva: UNAIDS, annual) www.unaids.org

Code of Practice on HIV/AIDS and the World of Work (Geneva: ILO, 2001) www.ilo.org

Criminal law, public health and HIV transmission: a policy options paper (Geneva: UNAIDS, 2002) www.unaids.org

From Principle to Practice: Greater Involvement of People Living with or Affected by HIV/AIDS (GIPA) (Geneva: UNAIDS, 1999) www.unaids.org

Gender mainstreaming in HIV/AIDS: taking a multisectoral approach (London: Commonwealth Secretariat and Maritime Centre of Excellence for Women's Health, 2002)

Guidelines for counselling children who are infected with HIV or affected by HIV and AIDS HIV Counselling Series No.7 (Ottawa: CIDA/CPHA, 2003)

Guidelines for Supporting HIV/AIDS Care, Treatment, and Support in Resource Limited Settings (Ottawa: CIDA, 2004)

Guidelines on Addressing HIV/AIDS in the Workplace through Employment and Labour Law Geneva: ILO, 2004) www.ilo.org/public/english/dialogue/ifpdial/downloads/papers/hivaids.pdf

Handbook for Legislators on HIV/AIDS, Law and Human Rights. (Geneva: UNAIDS and the Inter-Parliamentary Union, 1999) www.unaids.org

Handbook on National Human Rights Plans of Action (Geneva: Office of the High Commissioner for Human Rights, 2002) www.unhchr.ch/pdf/nhrap.pdf

HIV/AIDS & Human Development: South Africa. (New York: UNDP, 1998) hdr.undp.org/reports/detail_reports.cfm?view=577

HIV/AIDS and Human Rights: International Guidelines (Geneva: UNAIDS and Office of the High Commissioner for Human Rights, 1998) HR/PUB/98/1 See also *HIV/AIDS and Human Rights: International Guidelines - Revised Guideline 6* (Geneva: UNAIDS and Office of the High Commissioner for Human Rights, 2002) www.unaids.org

HIV/AIDS and the Rights of the Child General Comment No. 3 (Geneva: Committee on the Rights of the Child, 2003) www.unhchr.ch/html/menu2/6/crc/doc/comment/hiv.pdf

HIV and AIDS-related discrimination: a conceptual framework and implications for action (Geneva: UNAIDS, 2002) www.unaids.org

Integrating Gender into HIV/AIDS Programs (Geneva: WHO, 2002) http://www.who.int/gender/hiv_aids/hivaids1103.pdf

Just die quietly: domestic violence and women's vulnerability to HIV in Uganda (New York: Human Rights Watch, 2003) www.hrw.org

Mann J. Human Rights and AIDS: The Future of the Pandemic. In: Mann J et al (eds). *Health and Human Rights: A Reader.* New York: Routledge, 1999, at 216.

Monitoring the Declaration of Commitment on HIV/AIDS: guidelines on construction of core indicators (Geneva: UNAIDS, 2002) www.unaids.org/UNGASS/index.html

Networks for Development: Lessons learned from supporting national and regional networks on legal, ethical and human rights dimensions of HIV/AIDS (New York: UNDP, 2000) www.undp.org/hiv/publications/networks.htm

Policy for CIDA on Human Rights, Democratization and Good Governance (CIDA, 1996) www.acdi-cida.gc.ca/humanrights

Policy on Gender Equality (CIDA, 1999) www.acdi-cida.gc.ca/equality

Report on access to comprehensive care, anti-retroviral treatment (ARVs) and human rights of people living with HIV/AIDS in Latin America and the Caribbean Submission to the Inter-American Commission on Human Rights (LACCASO / Agua Buena / Center for Justice and International Law, 2002) www.laccaso.org

Reviewing programming on HIV/AIDS, human rights and development (Montreal: Canadian HIV/AIDS Legal Network, 2002)
http://www.aidslaw.ca/barcelona2002/humanrightsandHIV.pdf

Stigma and Discrimination: a Conceptual Framework and Basis for Action (Geneva: UNAIDS, 2002) www.unaids.org

Turning the tide: CEDAW and the Gender Dimensions of the HIV/AIDS Pandemic (UNIFEM, 2001)
http://www.genderandaids.org/downloads/topics/TurningTheTide.pdf

Web sites

AIDS Law Project, South Africa: www.alp.org.za
Canadian HIV/AIDS Legal Network: www.aidslaw.ca
Gender and HIV/AIDS (UNIFEM): www.genderandaids.org
Global Fund for AIDS, Tuberculosis and Malaria: www.theglobalfund.org
Human Rights Watch, USA: www.hrw.org (section on HIV/AIDS)
International Council of AIDS Service Organizations: www.icaso.org
Interagency Coalition on AIDS and Development, Canada: www.icad-cisd.com
International Labour Organization http://www.ilo.org/public/english/protection/trav/aids/
Joint United Nations Programme on HIV/AIDS (UNAIDS): www.unaids.org
United Nations Development Programme, HIV and Development Programme:
www.undp.org/hiv/
World Health Organization: www.who.int/hiv/en/

Annex – International Guidelines on HIV/AIDS and Human Rights

For further information refer to the explanatory text in the UNAIDS/OHCHR publication that accompanies the Guidelines (cited above). See also Handbook for Legislators on HIV/AIDS, Law and Human Rights (cited above), which gives practical guidance on implementation including checklists and examples of initiatives, many from developing countries.

GUIDELINE 1: 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.

GUIDELINE 2: 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 field of ethics, law and human rights, effectively.

GUIDELINE 3: States should review and reform public health laws to ensure that they adequately address public health issues raised by HIV/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.

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

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

REVISED GUIDELINE 6:

ACCESS TO PREVENTION, TREATMENT, CARE AND SUPPORT:

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

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

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

GUIDELINE 7: States should implement and support legal support services that will educate people affected by HIV/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.

GUIDELINE 8: States, in collaboration with and through the community, should promote a supportive and enabling environment for women, children and other vulnerable groups by addressing underlying prejudices and inequalities through community dialogue, specially designed social and health services and support to community groups.

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

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

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

GUIDELINE 12: 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 international level.