

# HIV/AIDS AND HUMAN RIGHTS



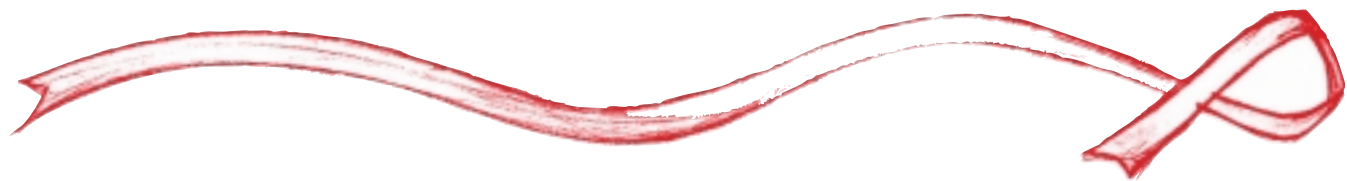
YOUNG PEOPLE in action



Joint United Nations Programme on HIV/AIDS

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# **HIV/AIDS AND HUMAN RIGHTS** *Young People in action*

A kit of ideas for youth organizations

This kit presents ideas for youth action on human rights and HIV/AIDS. It has been prepared in close consultation with young people from various youth organizations, in particular with students from the International Federation of Medical Students' Association and from the International Pharmaceutical Students' Federation.

Each community is different, and therefore not all suggestions will be suitable for every country or situation. We hope however that young people will find a starting point here for their own actions. No single agency or group can do everything, but we can all contribute in some way!

**(See Brochure 1 : Basics to Get Started)**

## **Public Education and Peer Education**

- To reject myths and misconceptions, and fight unnecessary HIV/AIDS related discrimination.
- To empower young people, to promote their rights and to inform them about how HIV can and cannot be transmitted, and how they can protect themselves.
- To discuss more openly sexuality and sexually transmitted diseases, as well as injecting drug use.
- To draw the attention of people in general and those in positions of authority in particular to accept the reality of HIV in our communities, and to recognise the rights of people living with HIV/AIDS.

**(See brochure 2 : Education and Communication)**

## **Advocacy**

- To challenge and change laws, attitudes and practices that are contrary to human rights and to effective action against HIV/AIDS.
- To campaign for better services for people living with HIV/AIDS, including access to medicine, counselling and other support(s) needed to defend the right to life and to health care.
- To support court action or other initiatives by people living with HIV/AIDS to demand their rights.
- To involve more and more people living with HIV/AIDS in campaigns and education activities.

**(See brochure 3 : Advocacy)**

## **Care and Support**

- To support and encourage people living with HIV/AIDS to participate in life in the community and to comfort those who are sick and may die through counselling, home visiting or other programmes.
- To inform people living with HIV/AIDS about their rights and about treatments.
- To give services and support to people who may be at risk, including women, children and young people, men who have sex with men, injecting drug users and commercial sex workers.
- To create spaces where people living with HIV/AIDS can meet, share concerns and information, and take joint action.

**(See brochure 4 : Care and Support)**

A **Glossary** is included in this package. It contains definitions of key terms used in the Guide.

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## **FOREWORD**

*"...The basis of discrimination against people living with HIV/AIDS is fear, and this fear comes mostly from wrong or distorted information... so, our first step had to be to correct misunderstandings about how HIV is transmitted..."*, says Franciscus, a young medical student from Indonesia, interviewed in this kit.

Indeed, when and where misinformation, taboos, prejudice and fear regarding HIV/AIDS predominate, fundamental human rights are repeatedly abused and violated. Young people are often those most vulnerable and exposed. At the same time and as shown in this kit, many young people are demonstrating their commitment to take up the challenge and reverse this situation successfully.

The last couple of years of the epidemic have confirmed the tremendous potential of young people to change the course of the epidemic. They are a powerful force for change in their own households, in the lives of their peers, and in the community.

Yet, much more is needed. We therefore hope that this kit will provide young people with information, motivation and inspiration to undertake the creative, daring and crucial action needed to make respect for human rights in the context of HIV/AIDS become a reality for all.



**Koïchiro Matsuura, Director-General,  
UNESCO.**



**Peter Piot, Executive Director, UNAIDS.**



## BASICS TO GET STARTED

> **I.** Human Rights and HIV/AIDS: the inter-linkage

> **II.** A platform for Action: the International Guidelines on HIV/AIDS and Human Rights

> **III.** Setting Priorities and Planning

Frequently Asked Questions on HIV/AIDS and Resources



# Human Rights and HIV/AIDS: The Inter-linkage

**H**IV/AIDS is one of a number of killer diseases, such as, malaria, tuberculosis, cancer and heart disease. What is different about HIV/AIDS is that it impacts not only the physical health of individuals, but also their social identity and condition. The stigma and discrimination surrounding HIV/AIDS can be as destructive as the disease itself.

Lack of recognition of human rights not only causes unnecessary personal suffering and loss of dignity for people living with HIV or AIDS but it also contributes directly to the spread of the epidemic since it hinders the response... For example, when human rights are not respected, people are less likely to seek counselling, testing, treatment and support because it means facing discrimination, lack of confidentiality or other negative consequences. It also appears that the spread of HIV/AIDS is disproportionately high among groups that already suffer from a lack of human rights protection, and from social and economic discrimination, or that are marginalised by their legal status.

## **...WHEN HUMAN RIGHTS ARE DENIED:**

...There is inadequate information

"Nobody ever explained to me about the risks. Girls are not supposed to ask about sexual matters. I had heard that the first time one cannot get pregnant or catch AIDS. Now it is too late for me."

Rushdeen, age 16, HIV-positive

...There is a lack of accessible and affordable medicines to protect the right to life and the right to health

"My son is HIV-positive. We know that there are drugs that could keep the disease away for perhaps a long time, but they are so expensive, we cannot afford them. We are angry that, because we are poor, our son may not be able to live for a long time"

Pablo, father of Eduardo, age 21

...There is discrimination and denial of the right to employment

"When my boss found out I was HIV positive, he asked me to leave. I explained the doctor had said there was no risk to other workers, but my boss said he did not want any trouble"

Sui, age 24, HIV-positive

...There is lack of privacy, confidentiality and loss of dignity

"One young woman went to hospital to have a baby and the doctors gave her a blood test and discovered she was HIV-positive. They told her husband, but they did not tell her. He rejected her and refused to let her see the children"

Meena, HIV/AIDS Counsellor



Since the HIV/AIDS epidemic began, over 60 million people have been infected with HIV and more than 20 million have died of AIDS. Despite wide-ranging interventions to curtail its further spread and to mitigate the impact of its effects, there are around 16 000 new infections each day and at the crux of the epidemic are young people, accounting for over 50 % of this daily toll. That is why young people are, and must be, at the centre of action on HIV/AIDS.

Silence, taboos and myths often surround HIV/AIDS because it is associated with private and intimate behaviours. In this context, many factors may restrict young people's full enjoyment of human rights and leave them particularly exposed to HIV infection, or vulnerable to needless suffering, if they are infected.

"Human rights consist of civil and political rights, as well as economic, social and cultural rights. They express recognition and respect for human dignity: they are therefore universal and belong equally to all human beings".

### Young people are at greater risk when...

- Access to clear and non judgmental information about sexually transmitted diseases, is difficult and restricted.
- Confidential HIV testing and counselling to find out if they are infected are unavailable or not adapted.
- They lack the power to refuse unwanted or unprotected sex, within and outside of marriage
- Sexual orientation or behaviour is concealed as a result of social, cultural, religious or legal prohibitions (for example, if they are homosexual)
- Local communities reject people living with HIV/AIDS and, as a result, secrecy becomes the norm.

Promoting human rights in the context of HIV/AIDS is not only an imperative of justice to overcome existing forms of discrimination and intolerance. It is also a tool to prevent the further spread of the epidemics. Indeed, human rights action can help to:

- Empower individuals and communities to respond to HIV/AIDS.
- Reduce vulnerability to HIV infection.
- Lessen the impact of HIV/AIDS on those infected and affected. ■





# A Platform for Action: The International Guidelines on HIV/AIDS and Human Rights

**U** NAIDS and the Office of the UN High Commissioner for Human Rights have developed a set of guidelines for Member States to assist them in designing programmes and policies and developing legislation that promote and protect human rights in the context of HIV/AIDS.

## THE INTERNATIONAL GUIDELINES ON HIV/AIDS AND HUMAN RIGHTS.

- Represent the collective recommendations of experts from the health, human rights, government and civil society, including people living with HIV/AIDS on how human rights should be protected and promoted, respected and fulfilled in the context of HIV/AIDS.
- Are based on existing human rights principles translated into concrete measures that should be taken as part of an effective HIV/AIDS strategy.
- Are not a formal treaty, but are based on international human rights treaties that must be observed by all states that have ratified them.
- Have been welcomed by the UN Commission on Human Rights and by human rights, development and health organizations around the world.

## THE INTERNATIONAL GUIDELINES ON HIV/AIDS AND HUMAN RIGHTS

### How can we contribute ?

**GUIDELINE 1** States should establish an effective national framework for their response to HIV/AIDS which ensures a co-ordinated, participatory, transparent and accountable approach, integrating HIV/AIDS policy and programme responsibilities across all branches of government.

*Refer to Brochure 3 - ADVOCACY for action ideas.*

**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.

*Refer to Brochure 2 - EDUCATION and COMMUNICATION, and Brochure 3 - ADVOCACY for action ideas.*

**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.

*Refer to Brochure 3 - ADVOCACY for action ideas.*

**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.

*Refer to Brochure 3 - ADVOCACY for action ideas.*

**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, emphasise education and conciliation, and provide for speedy and effective administrative and civil remedies.

*Refer to Brochure 3 - ADVOCACY and Brochure 2 - EDUCATION and COMMUNICATION for action ideas.*





**GUIDELINE 6** 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.

*Refer to Brochure 3 - ADVOCACY (Chapter 1: Calling for Government Action –Special Focus “Advocacy for equal access to drugs and medical treatment”) for action ideas.*

**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 utilise means of protection in addition to the courts, such as offices of ministries of justice, ombudspersons, health complaint units and human rights commissions.

*Refer to Brochure 3 - ADVOCACY (Chapter 2: Legal Action –Protecting Human Rights in the context of HIV/AIDS) for action ideas.*

**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.

*Refer to Brochure 4 - CARE and SUPPORT for action ideas.*

**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 stigmatisation associated with HIV/AIDS to understanding and acceptance.

*Refer to Brochure 2 - EDUCATION and COMMUNICATION (Chapter 1: Public Education Campaigns and Chapter 2: Peer Education) for action ideas.*

**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.

*Refer to Brochure 4 - CARE and SUPPORT for action ideas.*

**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.

*Refer to Brochure 3 - ADVOCACY (Chapter 1 Calling for Government Action) for action ideas.*

**GUIDELINE 12** States should co-operate 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.

*Refer to Brochure 3 - ADVOCACY (Chapter 3: Advocacy Beyond Borders-Introduction to the International Human Rights Machinery) for action ideas.*



## GROUP ACTIVITY

Case study may be a good exercise for your group to better understand how HIV and human rights are interrelated. You may seek examples of case situations and then discuss them within your group to see how and which human rights are significant in the context of HIV/AIDS...

Here are two sample case studies :

### 1. Case : Compulsory testing and discrimination

A 17 year old student has been awarded a scholarship to go to study law at a university in a foreign country. She is very excited by this opportunity. She informs her family and her friends...Two weeks before her date of departure she is advised by her sponsor that the university where she is going requires that she undergo a medical test at a specified clinic prior to her departure. At the clinic a number of blood and urine samples are taken. She is not informed about the type of tests that are being conducted.

Two days after the medical tests, she receives a letter that her scholarship has been cancelled because she has been found to be HIV positive and the country where she was to travel does not grant visas to people living with HIV. Furthermore, the university she planned to attend does not enroll students who are HIV positive.

Issues:

- Violation of her right to privacy by:
  - compulsory testing for HIV without her consent
  - passing on that information to third parties : the country and the university in question.
- Denial of the right to education on the basis of HIV status
- Violation of the fundamental right to non-discrimination

on the basis of HIV status by the country and the university in question.

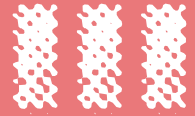
- Violation of the right to freedom of movement by the Country in question.

### 2. Case : Right to marry and raise a family

A 21 year old person has just completed his studies and has proposed marriage to his long time girl friend. She has accepted. He is HIV+ and she is aware of his HIV status. According to the tradition in their culture, before such a wedding can take place, the uncles have to consent. A month before the wedding, an uncle of the girlfriend who is a medical doctor informs the girl's family that the boy had once given a blood donation that was HIV+. The boy thus can not marry his niece. Both the boy and the girl are devastated by the fact that her uncle has informed most of the community about the boy's HIV status and also that he has withheld his consent for them to marry.

Issues:

- Violation of the fundamental right to non-discrimination on the basis of HIV status.
- Violation of the boy's and the girl's right to marry.
- Violation of the boy's right to privacy.



# Setting Priorities and Planning

## HOW DO YOU KNOW WHERE TO START ?

**T**his is the first challenge for everyone: how do you decide what to do? There are many different needs in each country or community. There are likely to be other agencies and groups already doing some work on similar issues. You will need to find out what needs to be done in order to protect the rights of people living with HIV/AIDS, to reduce the impact on those who are infected and to reduce vulnerability to infection by addressing factors that would lead to others being infected. You will also need to find out where the biggest gaps are, and what the most important/effective/useful programmes and activities are for your youth or student group. Of course, there is no single way to do this! There are many things that you could do, and many different ways of doing them, all of which could be good.

**Plan and carry out your work carefully, but do not wait for everything to be perfect.**

**Ask and learn from what has been done before, but also be ready to try new things and to go where the hearts and minds of your group lead you.**

## WHAT WORKS BEST

In nearly 20 years of work on HIV issues, a lot has been learned about the type of activity that is likely to work best. The following is a summary of some of the main lessons gained from practical experience in different parts of the world. Although these recommendations relate mostly to HIV prevention work, the same ideas apply to any activity that aims to change attitudes, beliefs and practices and care for those infected.

## THE MOST SUCCESSFUL PROGRAMMES :

- Involve people living with HIV, and the wider community, in all stages (in planning, implementation and evaluation)
- Recognise the realities that people face in their daily lives, and take people's own needs and interests as a starting point (rather than, for example, starting from your own assumptions about people's knowledge, beliefs or attitudes)
- Create open attitudes and accept how people are (rather than being critical or judgmental)
- Use positive images and friendly messages (rather than being frightening or authoritarian)
- Develop skills and knowledge (rather than telling people what to do)
- Win support from people in positions of authority (for example teachers, doctors, religious leaders, professional associations, government officials)
- Recognise that even well planned approaches sometimes fail (and, therefore, review progress and adjust the programme when needed)
- Carry out some form of evaluation, however brief (so that the activity can be replicated or improved by the same group or by others in the future)

Source : What Works Best?, in : *AIDS Action*, Issue 39, Health Link, United Kingdom, ....article by Peter Aggleton, Thomas Coram Research Unit, Institute of Education, 27/28 Woburn Square, London WC1OAA, UK.



## KEY STEPS IN SETTING PRIORITIES

Essential factors to be considered in setting your priorities:

- The views of people living with HIV/AIDS.
- The gaps - what is not being covered by others.
- Co-operation - opportunities to work with other groups.
- How much time and how many resources you have.
- What skills you have in your group.

## GROUP ACTIVITY

### Debating Priorities

This activity can be used to clarify the thinking of the group, to develop a climate where disagreement and opposing views are accepted, and to identify possible priorities for action.

- 1 • Sound out the target population including people living with HIV/AIDS. What do they see as the main priorities? Prepare around 6 statements, each describing a possible priority. For example:

*"We should campaign for legalisation of needle exchange schemes for injecting drug users"*

*"We should set up home-visit plan to support those who are sick and isolated"*

*"We should work with local employers to stop discrimination based on presumed and actual HIV/AIDS status"*

*"We should create opportunities for young women to discuss sexual health issues more openly"*

*"We should campaign for economic reform, because the only real solution is to end poverty"*

- 2 • Work in pairs. Give the full list of statements to each pair, and ask them to rank them in order of priority. Next ask pairs to form groups of four and compare their rankings. By this stage everyone will have had an opportunity to develop and clarify their views.
- 3 • Call everyone back together and ask the original pairs to report on the statements that they ranked in the first and last places. Note these on a flip chart or blackboard.
- 4 • Discuss the results. There may be some clear "firsts" and "lasts" which will help your decision-making. There may also be statements that were ranked first by some and last by others, and it is useful to discuss these, too. Finally, discuss the statements that were not ranked "first" or "last" by anyone.

**POINTS TO SHARE WITH PARTICIPANTS:** There are no "right answers". People's priorities will vary depending on their political, legal, social and economic position, experiences and values. During this activity everyone will have heard many new points of view and information. If the group does not feel ready to make a decision about priorities, it is a good idea to take some days or weeks to reflect and think over the issues before coming together again.

Source: "Living on the Edge", Coping with HIV and Drug Misuse, Training Guide, 1993, by the Community and Education Development Centre.



## KEY STEPS IN PLANNING

### A practical example.

The process of planning may seem complicated but in fact we all plan things all the time in our daily lives- we just don't write documents about them! Good planning is essential to the success of your project and is worth every minute of time that you spend on it. Here is an example of what a students association did to work out their action plan:

#### ■ Set a clear aim

"We had worked on identifying the priorities in our community and decided that, in order to combat discrimination of people living with HIV/AIDS, our first step had to be to correct misunderstandings about how HIV is transmitted and to get across that anyone can get infected. We felt this was particularly good because it would also help young people to avoid infection - and may even get us a little help with money from the university"

#### ■ Find out what the pre-project situation is, so that you can measure progress later.

"We knew that 'baseline surveys' or 'needs assessment studies' are used to identify where things stand at the start of a project. We did not have resources for any formal studies. Instead, we involved a group of students from different racial and social backgrounds, both boys and girls, in carrying out a 'listening survey' around the university for one week. They started discussions about HIV transmission wherever they saw a group of students, and listened carefully to the different opinions. They made brief notes of each discussion. We all met every evening to share our findings. We were amazed at how much we learned!"

#### ■ Be prepared to tackle the obstacles

"Through our student survey we found that, although most people knew that using condoms is important to avoid infection, they were still confused about how HIV is and is not transmitted,



and most were worried about having social contact with people with AIDS. Many people, particularly women, felt that it was not socially acceptable to ask questions.”

■ **Identify clearly the activities that will take place, when they will take place and who will do them.**

“We brought together people living with HIV/AIDS and other young people to discuss this. It was decided that our objectives would be to (a) seek the co-operation of the college authorities to put up humorous posters that gently challenged people’s fears and assumptions about sexual health and (b) involve young people living with HIV/AIDS as peer educators, talking to small groups of students.”

■ **Decide how you are going to check whether things are going well**

“We wanted to monitor our progress, so that we would know if our activities were having the kind of response we wanted. We decided that, after each gathering with a peer educator, we would ask participants to give us their feedback.”

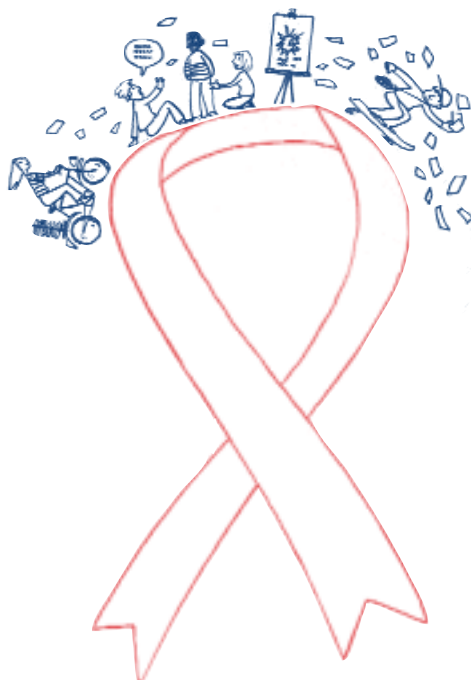
■ **Decide how you will evaluate the project after it ends.**

“We decided we would carry out a second survey after the project was completed, using the same ‘listening’ method as before. But this time we would start a group conversation about the posters and meetings with peer educators. We would then get feedback about whether people remembered seeing the posters, what they had thought of them, and what impact the peer educator meetings had had on those who had attended or on others who had heard about them.”

WE HAD A PLAN!!! Then we discussed who would do what when. This was the hardest part - but, in fact, people were really enthusiastic and there was a great sense of common purpose.

"Planning and evaluation should be done carefully, since you won't know where you are going without planning, and you won't know where you have been and where you need to go without evaluation."

F.Arifin. Counsellor of Medical Student Group on AIDS, Medical Faculty Diponegoro University (Semarang),IFMSA representative, Indonesia. ■



# Frequently asked questions about HIV/AIDS

## 1 • What is HIV and how is it transmitted?

HIV stands for human immunodeficiency virus and it is the virus that causes AIDS. People with HIV have what is called HIV infection. The most common ways that HIV is transmitted are by having unprotected sexual intercourse with an HIV infected person, by sharing needles or injection equipment with an injecting drug user who is infected with HIV, from HIV infected women to their babies during pregnancy, delivery or breastfeeding and finally through transfusions of infected blood. HIV is not transmitted through normal, day-to-day contact.

## 2 • What is AIDS? What causes AIDS?

AIDS – the Acquired Immuno-Deficiency Syndrome – is the late stage of infection caused by the Human Immunodeficiency Virus (HIV).

A person who is infected with HIV can look and feel healthy for a long time before signs of AIDS appear. But HIV weakens the body's defense (immune) system until it can no longer fight off infections such as pneumonia, diarrhea, tumours, cancers and other illnesses.

Today there are medical treatments that can slow down the rate at which HIV weakens the immune system (anti-retroviral treatment). There are other treatments that can prevent or cure some of the illnesses associated with AIDS, though the treatments do not cure AIDS itself. As with other diseases, early detection offers more options for treatment and preventative health care.

## 3 • Can I get AIDS from "casual contact" with an infected person?

No. This means that it is OK to play sports and work together, shake hands, hug friends or kiss them on the cheek or hands, sleep in the same room, breathe the same air, share drinking and eating utensils and towels, use the same showers or toilets, use the same washing water and swim in the same swimming pool. You cannot get infected through spitting, sneezing or coughing or through tears or sweat, or through bites from mosquitoes or other insects.

## 4 • Can someone infected with HIV look healthy?

There is no way of knowing whether someone is infected just by looking at them. A man or woman you meet at work, at school, in a sports stadium; in a bar or on the street might be carrying HIV – and look completely healthy. But during this time of apparent health, he or she can infect someone else.

## 5 • Is there a cure for HIV/AIDS?

There is no cure for HIV/AIDS. Although some very strong drugs are now being used to slow down the disease, they do not get rid of HIV or cure AIDS. The drug treatments are called Highly Active Anti-Retroviral Therapies (HAART). They are a mix of drugs that help to reduce the level of HIV in the blood. HAART can help to slow down HIV and keep some people healthy longer. Even though HAART work better than anything else so far, they do have some problems. They do not work for all people and it is not sure how well they will work over time, considering their high price and significant adverse effects.

## 6 • Is there a "morning after" pill that prevents HIV infection?

You may have heard about a morning after pill for HIV. In fact this is Post-Exposure Prophylaxis (PEP). It is not a single pill, and it does not prevent HIV/AIDS. PEP is a 4 week treatment that may reduce the risk of acquiring HIV for people who have been exposed to the virus. It does not eliminate the risk. So far, PEP has mostly been used to treat health care workers who have been exposed to HIV at work. Right now, there is no proof that PEP works, or that it is safe. PEP is not at all a solution to prevent HIV transmission.

## 7 • What should I do to protect myself from HIV?

Since there is no vaccine to protect people against getting infected with HIV, and there is no cure for AIDS the only certain way to avoid AIDS is to prevent getting infected with HIV in the first place. The best prevention method is the adoption of safe sex behaviour. Safe sex includes using a condom – but, using a condom correctly, and using one every time you have sex. You should learn how to use condoms and how to negotiate the use of condoms with your partner. For information about effective and healthy use of condoms, you should consult health services for young people and pharmacies. (Please also see: <http://www.unaids.org/hivaidinfo/faq/condom.html>)

## 8 • What are the risks of getting HIV through injecting drug use?

The only way to be sure you are protected against HIV is not to inject drugs at all. If you do inject drugs, you can avoid the very high risk of being exposed to HIV by always using sterile, un-used needles and syringes, and using them only once.





### **9 • What should I do if I think I might already have HIV?**

If you think you might have HIV, or if you have had unprotected sex, you should ask your physician about getting an HIV blood test and some counselling. If you prefer to check it out yourself, many cities have testing centres where you can get an HIV test and some good confidential counselling. It is essential to know whether you have been infected. If you are infected, early detection will permit you to get full and proper medical care. With proper care, people with HIV infection can live for many years. It is also essential to know whether you are infected to avoid infecting others through blood donation, unprotected sex or through needle sharing.

### **10 • What if I test positive for HIV?**

If you test positive for HIV, the sooner you take steps to protect your health, the better. Prompt medical care may delay the onset of AIDS. There are a number of important steps you can take immediately to protect your health. See a doctor, even if you do not feel sick. There are now many drugs to treat HIV infection and help you maintain your health. Cf. advocacy – a basic healthcare package

### **11 • What should I do if I know that someone has HIV or AIDS?**

People with HIV are part of society. They can continue their lives, do their jobs as well as they could before they were infected. They look and feel perfectly healthy for a long time. People with HIV should be treated just like anyone else. If you know that someone has HIV or AIDS, you should respect that person's privacy and do not tell no one about his or her infection. We all need to learn to live with HIV and AIDS. This involves understanding people with HIV/AIDS and giving them love and support, not prejudice and rejection. ■

# Resources

- 1 • Please see the **Glossary** brochure for the definition of key terms used in the Guide.
- 2 • The texts of international human rights treaties, and a list of countries that have ratified them, are available on the Internet site of the **UN Office of the High Commissioner on Human Rights**. **web-site** : [www.unhchr.ch](http://www.unhchr.ch)  
For the text of international human rights treaties, and status of ratification see: [www.unhchr.ch/html/intlinst.htm](http://www.unhchr.ch/html/intlinst.htm)
  - **UN Office of the High Commissioner for Human Rights, OHCHR-UNOG**  
8-14 Avenue de la Paix, CH-1211 Geneva 10, Switzerland  
Tel : 41 22 917 9000 Fax : 41 22 917 9016
  - **UNESCO** publication “*Human Rights – Major International Instruments status as at 31 May 2001*” is available free of charge at :  
**Division of Human Rights, Democracy, Peace and Tolerance**  
Sector of Social Science and Human Sciences  
**UNESCO**  
7, Place de Fontenoy, 75352 Paris 07 SP, France  
Fax : 33 1 45 68 57 26  
and also via Internet : [www.unesco.org/human\\_rights/index.htm](http://www.unesco.org/human_rights/index.htm)
- 3 • The full text of the **International Guidelines on HIV/AIDS and Human Rights** can be obtained as follows:
  - **UNAIDS**  
20 Avenue Appia CH-1211 Geneva 27 Switzerland  
Tel : 41 22 791 3666 Fax : 41 22 791 4187  
via Internet : [www.unaids.org/publications/documents/human/law/hrightze.doc](http://www.unaids.org/publications/documents/human/law/hrightze.doc)  
Or try any UN representation in your country.
- 4 • “*NGO Summary of the International Guidelines on HIV/AIDS and Human Rights*” and “*An Advocate’s Guide to the International Guidelines on HIV/AIDS and Human Rights*” can be obtained as follows :
  - **ICASO** Central Secretariat  
399 Church St, 4th Floor Toronto, ON Canada M5B 2J6  
Tel : + 1 416 340 8484 Fax : 1-416 340 8224  
via Internet : [www.icaso.org/actionpack.html](http://www.icaso.org/actionpack.html)
- 5 • “*Human Rights: Questions and Answers*”: simply presented information about internationally agreed human rights principles and systems. It can be obtained from UNESCO in your country or from UNESCO headquarters.
  - **UNESCO**,  
7 Place de Fontenoy 75352 Paris 07 SP France  
Tel : 33 1 45 68 10 00 Fax : 33 1 45 67 16 90  
via Internet : [www.unesco.org/human\\_rights/aj.htm](http://www.unesco.org/human_rights/aj.htm)
- 6 • **USEFUL WEB-SITE LINKS CONCERNING GENERAL ISSUES ON HIV/AIDS :**  
(For specific topics, please see the relevant brochure)
  - **UNAIDS** : The Joint United Nations Programme on HIV/AIDS.  
20 Avenue Appia CH-1211 Geneva 27 Switzerland  
Tel : 41 22 791 3666 Fax : 41 22 791 4187  
**e-mail/General Information** : [unaids@unaids.org](mailto:unaids@unaids.org)  
**web-site** : [www.unaids.org](http://www.unaids.org) (with links to the UNAIDS cosponsors)

**EIGHT UN SYSTEM ORGANIZATIONS (THE UNAIDS COSPONSORS) :**

  - **UNICEF** (United Nations Children’s Fund)  
UNICEF House, 3 United Nations Plaza New York, New York 10017 U.S.A.  
Tel : 1-212 326.7000 – Switchboard UNICEF House Fax : 887.7465  
**web-site** : [www.unicef.org](http://www.unicef.org)





**UNICEF has a website for their health programme on HIV/AIDS at:**

**[www.unicef.org/programme/health/index.htm](http://www.unicef.org/programme/health/index.htm)**

• **UNDP** (United Nations Development Programme)

HIV and Development Programme

304 East 45th Street Room FF – 616 New York, NY 10017 USA .

Tel: 1 212 906 66 64 Fax: 1 212 906 63 36

**e-mail : [hdp.registry@undp.org](mailto:hdp.registry@undp.org)**

**web-site : [www.undp.org](http://www.undp.org)**

UNDP's HIV and Development Programme can be viewed at : **[www.undp.org/hiv/](http://www.undp.org/hiv/)**

• **UNFPA** (United Nations Population Fund)

220 East, 42nd Street New York, N.Y. 10017 USA.

**e-mail: [hq@unfpa.org](mailto:hq@unfpa.org)**

**web-site : [www.unfpa.org](http://www.unfpa.org)**

UNFPA has an AIDS clock which can be viewed at : **[www.unfpa.org/modules/aidsclock/index.htm](http://www.unfpa.org/modules/aidsclock/index.htm)**

• **UNDCP** (United Nations Office for Drug Control and Crime Prevention)

Vienna International Centre PO Box 500 A-1400 Vienna Austria

Tel: 43 1 26060 0 Fax: 43 1 26060 5866

**e-mail : [odccp@odccp.org](mailto:odccp@odccp.org)**

**web-site : [www.undcp.org](http://www.undcp.org)**

UNDCP has a global youth Network at:

**[www.undcp.org/global\\_youth\\_network.html](http://www.undcp.org/global_youth_network.html)**

• **ILO** (International Labour Organization)

4 route des Morillons CH-1211 Geneva 22 Switzerland

Tel: 41 22 799 61 11 Fax: 42 22 798 86 85

**e-mail : [ilo@ilo.org](mailto:ilo@ilo.org)**

**web-site : [www.ilo.org](http://www.ilo.org)**

ILO has a web page on HIV/AIDS and the world of work:

**[www.ilo.org/public/english/protection/trav/aids/](http://www.ilo.org/public/english/protection/trav/aids/)**

• **UNESCO** (United Nations Education Science and Culture Organization)

7 Place de Fontenoy 75352 Paris 07 SP France

Tel: 33 1 45 68 10 00 Fax: 33 1 45 67 16 90

**web-site : [www.unesco.org](http://www.unesco.org)**

UNESCO HIV/AIDS and human rights: e-space for young people can be viewed at:

**[www.unesco.org/hiv/human\\_rights](http://www.unesco.org/hiv/human_rights)**

• **WHO** (World Health Organization).

The World Health Organization Headquarters Office in Geneva,

Avenue Appia 20, CH-1211 Geneva 27 Switzerland

Tel: 41 22 791 21 11 Fax: 41 22 791 3111

**web-site : [www.who.int](http://www.who.int)**

For the addresses of WHO Regional Offices and other WHO Offices see : **[www.who.int/regions](http://www.who.int/regions)**

• **The World Bank**

1818 H Street, N.W. Washington, DC 20433 U.S.A.

Tel: (202) 477-1234 fax: (202) 477-6391

**e-mail : [feedback@worldbank.org](mailto:feedback@worldbank.org)**

**web-site : [www.worldbank.org](http://www.worldbank.org)**

For World Bank Resources on HIV/AIDS visit : **[www.worldbank.org/afr/aids/resources.htm](http://www.worldbank.org/afr/aids/resources.htm)**

■ **ICASO** (International Council of AIDS Service Organizations)

399 Church St, 4th Floor, Toronto, Canada M5B 2J6.

Tel: (1 416) 340-2437,

**e-mail: [info@icaso.org](mailto:info@icaso.org)**

**web-site: [www.icaso.org](http://www.icaso.org)**

**ICASO HAS REGIONAL OFFICES IN ASIA, AFRICA, EUROPE AND LATIN AMERICA :**

• **APCASO** (Asia/Pacific Council of AIDS Service Organization) c/o Malaysian AIDS Council

12 Jalan 13/48A The Boulevard Shop Office of Jalan Sentul 51000 Kuala Lumpur, Malaysia

Tel: 60 3 4045 1033 fax: 60 3 4043 9178

**e-mail: [apcaso@pd.jaring.my](mailto:apcaso@pd.jaring.my)**

**web-site: [www.31stcentury.com/apcaso](http://www.31stcentury.com/apcaso)**

• **AFRICASO**

ENDA Tiers Monde

54, rue Carnot, B.P. 3370 Dakar, Senegal

Tel: (221) 823-1935 Fax: (221) 823-6615

**e-mail: [africaso@enda.sn](mailto:africaso@enda.sn)**

**web-site: [www.africaso.org](http://www.africaso.org)**

• **EUROCASO** Groupe sida Geneve

17 rue Pierre-Fatio CH-1204 Geneva, Switzerland

Tel: (41-22) 700-1500 Fax: (41-22) 700-1547

**e-mail: [eurocaso@hivnet.ch](mailto:eurocaso@hivnet.ch)**

**web-site: [www.hivnet.ch/eurocaso](http://www.hivnet.ch/eurocaso)**

• **ACCSI** Acción Ciudadana contra el SIDA

ACCSI, Av. Rómulo Gallegos, Edif. Maracay, Apto. 21, El Marqués Caracas 1071 – Venezuela

Tel: (58-2) 232 7938 Tel/Fax: (58-2) 235 9215

**e-mail: [laccaso@internet.ve](mailto:laccaso@internet.ve)**

**web-site: [www.laccaso.org](http://www.laccaso.org)**

■ **Canadian HIV/AIDS Legal Network**

417, rue Saint-Pierre, bureau 408 Montreal QC H2Y 2M4 Canada

Tel: 514 397 6828 Fax: 514 397 8570

**e-mail: [enolet@aidslaw.ca](mailto:enolet@aidslaw.ca)**

**web-site: [www.aidslaw.ca](http://www.aidslaw.ca)**

■ **The European Commission EU HIV/AIDS programme in developing countries**

**web-site: [www.europa.eu.int/comm/development/aids](http://www.europa.eu.int/comm/development/aids)**

■ **EIC Network**: European Information Centre 'AIDS and Youth' (EIC). The EIC is funded by the Programme 'Community Action on the prevention of AIDS and certain other Communicable Diseases' (EC/DGV) of the European Commission and the Netherlands AIDS Fund.

**Netherlands Institute for Health Promotion and Disease Prevention (NIGZ)**

**European Information Centre 'Aids & Youth' (EIC)**

P.O. Box 500 3440 AM Woerden The Netherlands

Tel: 31 348 437600 Fax: 31 348 437666

**e-mail: [eic@nigz.nl](mailto:eic@nigz.nl)**

**web-site: <http://195.108.118.21/index.html>**

■ **FOCUS on Young Adults** **web-site: [www.pathfind.org/focus.htm](http://www.pathfind.org/focus.htm)**

■ **Harvard AIDS Institute** **web-site: [www.hsph.harvard.edu/hai/](http://www.hsph.harvard.edu/hai/)** ■



**NOTES:**

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Joint United Nations Programme on HIV/AIDS

**UNAIDS**  
UNICEF • UNDP • UNFPA • UNDCP  
UNESCO • WHO • WORLD BANK

UNAIDS • 20 avenue Appia - 1211 Geneva 27, Switzerland • Telephone : (+41 22) 791 46 51 - Fax : (+41 22) 791 41 87 •  
E-mail : [unaids@unaids.org](mailto:unaids@unaids.org) • Internet : <http://www.unaids.org>

> I. Public Awareness Campaigns to Fight Discrimination in the Community



## EDUCATION AND COMMUNICATION

> II. Peer Education: Creating New Spaces for Youth Dialogue on HIV/AIDS and Human Rights

> III. Talking about HIV/AIDS and Respecting Freedom of Thought and Religion



# Public awareness campaigns to fight discrimination in the community

**C**onnected as it is to potent taboos as sex and death, HIV often inspires fear. There has been a tendency to think of the epidemic as "a scourge", "a plague" and "a punishment" and to find groups to blame for it: white foreigners, black foreigners, homosexuals, truck drivers, the young, the promiscuous, the uneducated, etc.

Unclear and distorted information about how HIV is transmitted builds on fear and leads to prejudice and discrimination. For example, people living with HIV/AIDS may be turned away from jobs, schools, hospitals or social groups. Fear of rejection isolates those vulnerable to HIV/AIDS and makes it more difficult to access help, information and early treatment. Human rights are violated as people are deprived of their inherent right to work, have access to health care and medicines, have access to education and be treated with dignity and respect. In these ways, negative impact of the epidemic is compounded.

## To overcome fear and prejudice, public awareness, education and communication are essential !

Public awareness is key to breaking secrecy and silence, challenging wrong assumptions, clearing confusion and motivating people to think differently. Public awareness is also important to advocate governmental action on **HIV/AIDS and Human Rights**. Governments need to implement the International human rights principles and the public needs to foster government accountability. For example, governments should develop policies and legislation that prohibit discrimination based on one's HIV status and should take action against employers, educational institutions, hospitals and other institutions that exclude people living with HIV/AIDS. (Guideline 5). Governments should also provide financial and other support for the prevention of HIV/AIDS in particularly vulnerable populations such as injecting drug users, sex workers and men who have sex with men. (Guideline 2).

## CHALLENGING MYTHS, TABOOS AND PREJUDICES

What causes discrimination? In the context of HIV/AIDS, discrimination appears to be caused mainly by:

- Misguided fears of catching the virus through social contact, usually due to misinformation
- Prejudice about the presumed lack of morality of those who are infected
- Racism, homophobia, classism, sexism
- Laws or social rules that reflect one or more of the above.

Challenging social attitudes or beliefs is not easy and it is important to understand how to approach these sensitive topics publicly in each culture. The aim has to be to make people reflect on and question their own attitudes, but not to offend or to turn people away.

## EXPLORING SOURCES OF PREJUDICE AND DISCRIMINATION

One useful starting point for planning a public awareness campaign targeting youth, is to identify the sources of discrimination in your own society. You may want to explore these questions:

- **Are there beliefs and behaviour norms in your society that generate negative attitudes towards specific groups of young people or youth in general and that increase their vulnerability to HIV/AIDS.**

*Beliefs and cultural references can be used to justify prejudice or discrimination in the context of HIV/AIDS. Here are some examples of popular beliefs that generate prejudice :*

- "Sex education leads to sexual promiscuity"
- "Girls who carry condoms have low morals"
- "AIDS is a punishment from God"
- "If he's got AIDS he must have done something bad".

- **Which false assumptions and beliefs about HIV transmission and AIDS contribute to rejection of and discrimination against people living with HIV/AIDS and increase the vulnerability of young people ?**

*Here are some myths about AIDS that are still common today:*

- "You can catch AIDS from toilet seats"
- "People who have AIDS should be in isolated wards"
- "You can catch AIDS from insect bites"



“You can't get AIDS the first time you have sex”  
 “If the woman gets ill first, it means that she has been unfaithful”  
 “You can get cured from AIDS if you have sex with a virgin”  
 “It's necessary to avoid touching someone who has HIV/AIDS”



States should promote the wide and ongoing distribution of creative education, training and media programmes explicitly designed to change attitudes of discrimination and stigmatisation associated with HIV/AIDS to understanding and acceptance. Guideline 9, International Guidelines on HIV/AIDS & Human Rights.

**GROUP ACTIVITY**

**Identifying social and cultural dimensions of prejudice and discrimination related to HIV/AIDS in your community**

(Activity designed by the organization “World Neighbours” together with local partners in Nepal)

**PURPOSE:** to identify and to understand in a practical way that HIV/AIDS and other sexual health problems are not only a medical but also a social issue.

**MATERIALS:** • cards describing causes of problems related to HIV/AIDS in your community (these may have been prepared by brainstorming within the group).  
 • a large chart with 3 columns, each with a drawing/title indicating (1) medical (2) social and (3) medical and social.

**PROCEDURE:** Facilitator explains the three categories and gives some examples. Participants place each card under one column. When finished, participants discuss the results. ( In one workshop in Nepal, one of the conclusions was that medical issues were more openly recognised and were included in several programmes, but social issues tended to be neglected).

This is a partial view of how the chart looked in the Nepal workshop :

**["medical" issues]**

- insufficient health services
- lack of contraceptives
- lack of privacy
- infections from dirty facilities

**["social" /"medical" issues]**

- unprotected sex
- poor nutrition
- not knowing the ill effects of alcohol
- lack of education
- secrecy
- too many children

**["social" issues]**

- big families
- bad relations
- conservative social customs
- burden of work on women
- superstition
- alcohol
- religious traditions
- gender discrimination
- women's lack of confidence
- poverty

Source : Responding to Reproductive Health Needs : Participatory Approach for Analysis and Action, World Neighbours, email : order@wn.org ; website : www.wn.org. Quoted in : PLA Notes No. 37, International Institute for Environment and Development - see Resources, below.





## INTERVIEW

### Indonesian students tackle public fears around HIV/AIDS

Fransiscus Arifin, a young medical doctor from Indonesia, has helped to develop an AIDS education programme at the Medical Faculty of Diponegoro University. The "AIDS Awareness Group" works with medical students and with the general public.

**Question - One of your objectives is to create a supportive community attitude towards people living with HIV/AIDS. What does this programme consist of ?**

We realised that the basis of discrimination against people living with HIV/AIDS is fear, and that this fear comes mostly from wrong or distorted information.

We do many different things to reach the public : poster competitions, speech competitions, public ceremonies such as the World AIDS Candlelight event, distribution of leaflets, and running information stands in public areas such as bus terminals, markets, etc. These activities are designed to provide information and to create public interest in receiving correct information.

**Q - You work together with other organizations. How is this important?**

Networking is very important. Resources that are lacking in one group can be filled by others and vice-versa, and there are a lot of groups working in HIV/AIDS. For example, we get experts to provide medical information by working together with the hospital and faculty.

We can also work with the Junior Red Cross to reach school students.

**Q - What do you consider the most successful part of your programme and why?**

I consider that the most successful program was the competition we held for high school students. We received positive feedback from them, and they showed great enthusiasm in understanding HIV/AIDS. This has been followed up with series of discussions, which will form the basis for a training kit for non-medical students.

**Q - What advice would you give to students who want to start an HIV/AIDS education programme ?**

I think the hardest part is to take the first step. I would start with small-scale activities, by way of a warm-up. The second hardest part is to sustain activities. We have had ups and downs in our activities, because of the tight curriculum in a medical school, but it is possible for some people to keep up the work while others take a break. Recruitment is not a big problem if you are in a student organization, you will find that many people are interested. Good luck, and health for all!

*AIDS Awareness Group will be glad to share experiences with other youth organizations. You may contact F.Arifin at: [f\\_arifin@hotmail.com](mailto:f_arifin@hotmail.com); or the group at: [spakita@yahoo.com](mailto:spakita@yahoo.com)*



## CREATING EFFECTIVE CAMPAIGN MESSAGES

If you are planning a public campaign with posters, leaflets, stickers, banners or television spots, your choice of message could mean the success or failure of your activity. Youth friendly messages that involve aspects of the youth culture in your society will probably draw the attention of young people more than instructional/didactic messages.

Designing an effective public message is a challenging task and can be a great team activity. Many public awareness campaigns fail because the message is vague, negative, or unsuitable. Here are some tips for avoiding failure:

### Tip 1: Choose Your Words Carefully

Be positive. The list below provides examples of words that reinforce negative attitudes and proposes more neutral and positive expressions:

Instead of	Use
"Victim"	> person living with HIV or AIDS
"Plague, Scourge"	> epidemic
"Monster, Enemy"	> serious disease
"Pity, charity"	> solidarity, respect for human rights

### Tip 2: Choose Your Images Carefully:

Be aware that some images may reflect the preconceptions or stereotypes that we are trying to combat, for example:

- A picture of someone dying of AIDS may give the impression that the majority of infected people are very sick. In reality, most infected people can look and live normally for a long time.
- A picture that depicts AIDS with grotesque images of monsters or skulls can be counter-productive: people may not be attracted to read it, and may turn away. Many people think "It won't happen to me"
- A picture of someone with AIDS that inspires pity may not be what people living with HIV/AIDS want or need: it is respect and dignity that they need most.

### Tip 3: Test the Final Product

Once the poster or other product that you have been working on is ready, ask members of the target group the following questions:

- What is your immediate reaction to the message?
- Who is the message for ?
- Who is the message from ?
- What did you like about the message ?  
(Consider: Colour, Shape, Content, Language, Medium, Other)
- What did you not like ?  
(Consider: Colour, Shape, Content, Language, Medium, Other)
- What would you add to the message ?
- What would you take away ?
- Do you feel represented/good about this material ?



## Advice on effective campaign messages by Intercambios, a youth agency working with injecting drug users in Argentina.

### In order to develop an effective message:

- You must involve people from the target population.
- It must be tested with other members of the same population.
- It must be tested also with other people who will see the message (for example, with adults who may visit the same area: are they likely to find it offensive?)

### No message can talk to everyone!

- Each group has its own cultural attitudes, language and social codes.
- The more the message is drawn for a specific audience, the better.
- Remember that the same message could mean different things to different people.
- Look at all the possible interpretations.

### It is possible to avoid the most common mistakes:

To prepare strategies in the office would lead to:

- Not taking into account the cultural medium of the target group
- Not using the communication codes or channels of the target group
- Not testing sufficiently and having a message that is vague or ambiguous
- Not taking into account possible counter-reactions or negative impacts
- Not learning from the experience of others before starting the activity
- Not recognising how people really behave
- Not evaluating the results"

*Intercambios, Corrientes 2548, 10.E, Buenos Aires, Argentina,  
e-mail [intercam@civici.com.ar](mailto:intercam@civici.com.ar)*

States should promote the wide and ongoing distribution of creative education, training and media programmes explicitly designed to change attitudes of discrimination and stigmatisation associated with HIV/AIDS to understanding and acceptance. Guideline 9, International Guidelines on HIV/AIDS & Human Rights.

## KEY PRACTICAL TIPS FOR PUBLIC EDUCATION CAMPAIGNS

- Consult and involve relevant community group, including people living with HIV/AIDS.
- Make your messages short, direct and adapted to the target group's lifestyle and motivations.
- Test images and messages by getting reactions from a representative sample of people.
- Be provocative and controversial if necessary, but avoid offending others.
- Present positive images; remember that people living with HIV and AIDS have the right to lead full lives for a long time.
- Aim to motivate people - this works better than telling them what they have to do.

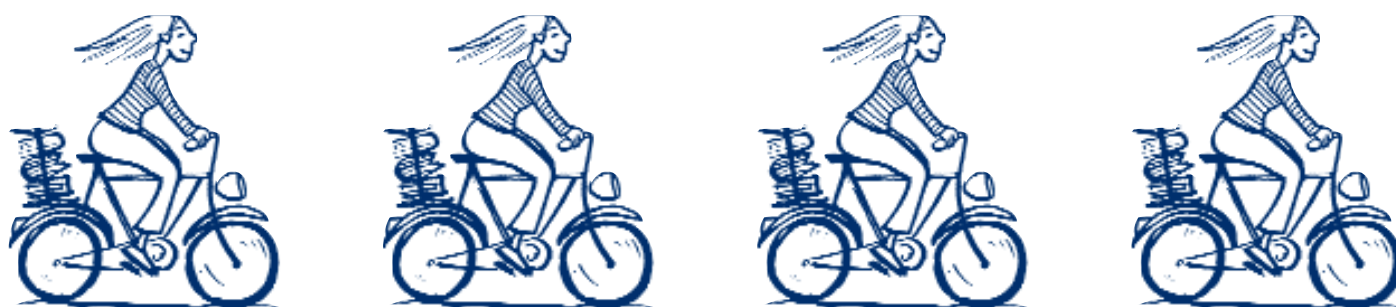




## RESOURCES:

Please refer to the “**Resources**” in the brochure “Basics to Get Started” for useful web-sites concerning HIV/AIDS issues in general.

- 1 • **Public Campaign Manuals:** Many books and manuals have been written by experienced public campaigners and by campaigning organizations which give useful step-by-step advice. Try approaching a campaigning organization in your country, it may be able to provide direct advice or to supply or recommend appropriate reading material.
- 2 • “*Strengthening Community Responses to HIV/AIDS, Toolkit, 2000*”, **UNDP**. It can be obtained via internet :  
[www.undp.org/hiv/publications/index.htm](http://www.undp.org/hiv/publications/index.htm)
- 3 • Srinivasan L, and Narayan D, *Participatory Development Tool Kit : Materials to Facilitate Community Empowerment*. Published by the World Bank, 1994.  
To order by mail : **The World Bank**  
P.O. Box 960 Herndon, VA 20172-0960, U.S.A.  
Tel: 1-800-645-7247 or 703-661-1580 ; Fax 703-661-1501.  
To order by e-mail : [books@worldbank.org](mailto:books@worldbank.org)  
**web-site : [www.worldbank.org](http://www.worldbank.org)**
- 4 • Aboagye-Kwarteng T, Moodie R, eds. *Community Action on HIV : a Resource Manual for HIV Prevention and care*. Fairfield VIC, Australia, Macfarlane Burnet Centre for Medical Research for AusAID, 1995. ( Designed for NGOs. How to address critical issues and questions, with proposals and application of the logic of good project design and implementation in HIV prevention and care)
- 5 • “*Human Rights and HIV/AIDS: Effective Community Responses*”, May 1998, **Human Rights Internet**,  
8 York Street, Suite 302, Ottawa, Ontario, Canada.
- 6 • “*Participatory Learning and Action Notes: Sexual and Reproductive Health*” (PLA Notes No. 37, February 2000) , is an excellent compilation of practical information written by community workers and project leaders from different parts of the world. Published by **The International Institute for Environment and Development (IIED)**. IIED may send copies of individual articles at no charge to local NGOs in developing countries. Contact them with details of your particular questions:  
**IIED**  
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**web-site with order details: [www.iied.org/bookshop](http://www.iied.org/bookshop)**
- 7 • **Web-sites on participatory learning :**  
**Strategies for Hope series : [www.stratshope.org](http://www.stratshope.org)**  
**Participation Group Page : [www.ids.ac.uk/ids/particip/home/index.html](http://www.ids.ac.uk/ids/particip/home/index.html)**  
**UNDP : [www.undp.org/hiv/index.html](http://www.undp.org/hiv/index.html) ■**





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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 stigmatisation associated with HIV/AIDS to understanding and acceptance. Guideline 9, International Guidelines on HIV/AIDS & Human Rights.





# Peer education: Creating new spaces for youth dialogue on HIV/AIDS and human rights

**Y**oung people may find it difficult to obtain clear and scientifically correct information about HIV/AIDS, sexual behaviour, or other topics that may be sensitive in their society. Where information is available, it may be given in a manner that is authoritarian, judgmental, or non-adapted to the young people's values, viewpoints and lifestyle. This situation threatens young people's right to information.

One effective way to break these communication barriers is peer education. Peer Education is a dialogue between equals. It involves members of a particular group educating others of the same group. For example, young people share information with each other, some acting as facilitators of the discussions. It usually takes the form of an informal gathering of people who, with the help of the peer educator, (someone of a similar age or social group), discuss and learn about a particular topic together. Peer education works well because it is participatory, meaning that it involves people in discussion and activities. **People learn more by doing than by just getting information.** Peer education is therefore a very appropriate way to communicate human rights in the context of HIV/AIDS and to empower young people to take action. Examples of participatory activities used in peer education are games, art competitions and role plays. All of these can help people to see things from a new perspective without "being told" what to think or do.

## INTERVIEW

### Talking to a peer educator

Selma, a medical student from Bosnia attending university in Norway, is an experienced peer educator. Here she tells us about her experience:

**Question - In what way is peer education useful for your work on HIV/AIDS?**

Peer education works very well for students and young people. Sharing a conversation with people of the same age or social group you can be more relaxed, and, for example, you can ask questions that would be difficult to ask to an adult.

**Q - What is the role of the peer educator?**

The main role of the peer educator is to help participants to feel comfortable and able to take part in a dialogue, even if the topic is difficult. The peer educator is also there to share information, and to increase the knowledge of the participants on the basis of their own questions and concerns.

**Q - What knowledge and skills do you need to be a peer educator?**

It is important to have had some training as a group facilitator or peer educator. You also need a general knowledge of the subject, to answer questions clearly, but it is not necessary to be an expert; it is better to refer people to organizations or leaflets where more information can be found.

**Q - How do you organise a peer education programme?**

In our organization, we decided to work in co-operation with secondary schools and youth clubs. We normally organize the activity together with the teacher or youth leader. We try to find out as much as possible about the group: their concerns, risk behaviours, experiences, existing knowledge. We decide in advance whether it is better to have boys and girls together or to work in separate gender groups. The teacher or youth leader does not attend the session.

**Q - How do you get a session started?**

Sometimes we start with a game, which is great to get people laughing and relaxed. To start the discussion about sexual behaviour, we draw a picture of the male and female reproductive organs and ask people to name them. We ask them to give not only the names used in Biology books but also any slang names used by young people. This gets everyone laughing and helps them to relax too!

**Q - What do you do if people are finding it difficult to take part in the dialogue?**

It is better to let people define their own concerns, ask their own questions. However, if the group needs a little help getting the conversation started, it can be useful to divide people into smaller groups and to give them specific questions to talk about. For example: What do you think about using condoms in sexual intercourse? What are the reasons for and against visiting a friend who has HIV-AIDS?

**Q - What special tips would you give to other peer educators?**

Peer educators need the skills to bring out the views and concerns of the participants. It is important to realise that our role is to give information and let young people make their own decisions based on facts. We should always try not to be directive, we are their peers, not their parents! Make sure participants know that there will be no report of the session made for anyone. Ask them to try not to discuss the opinions of particular individuals outside of the group, but also tell them that confidentiality cannot be guaranteed, so the discussion should be about general and not personal situations. If possible, give out information about where individuals who want to discuss a personal situation can get confidential advice. At the end do not forget to ask them kindly, to fill out the evaluation forms you prepared for them. It makes work much easier next time! Good luck!







States should promote the wide and ongoing distribution of creative education, training and media programmes explicitly designed to change attitudes of discrimination and stigmatisation associated with HIV/AIDS to understanding and acceptance. Guideline 9, International Guidelines on HIV/AIDS & Human Rights.

**GOOD PRACTICE**

## National Network of Adolescents on sexual and reproductive health in Argentina

A group of adolescent peer educators trained by and working with FEIM (Fundación para el Estudio e Investigación de la Mujer) have started a national network of adolescent peer educators to work and train together, to promote human rights, especially sexual and reproductive rights, and to develop citizenship skills in adolescents so that they can participate more fully in democratic processes.

"According to our research, Argentine adolescents talk about sexual and reproductive matters principally with their peers, to a lesser degree with their

parents (mostly with the mother), and very rarely with their teachers".

"In our country adolescents have no access to information about sexuality, since there is no sex education in schools. Sexuality is still a taboo in many developing countries and many cultural and religious barriers still remain."

"One of the challenges of the network is to advocate for sex education in schools, because this could help decrease the risk of sexually-transmitted diseases, delay the onset of sexual activity, and avoid unwanted adolescent pregnancies."

Source: With thanks to FEIM, Parana 135, piso 3 "13", 1017 Buenos Aires, Argentina. Tel. (5411) 43722763, fax (5411) 43755977, e-mail: feim@ciudad.com.ar; web-site: www.feim.org.ar





## USING GAMES FOR LEARNING

Group games are a great way to learn, and they can be fun, too. They work particularly well at the start of a peer education session, but they are also valuable as educational activities on their own. Here are 2 examples intended for illustration only. There are many good activity books designed for trainers and peer educators, in which different games and activities are explained in detail. Look for one that is suitable for your community (cf. Resources).

### GROUP ACTIVITY

#### Group games

##### Game 1: "The Ideal People"

**PURPOSE:** To encourage acceptance of diversity.

**DESCRIPTION:**

- The group is divided into small teams. The teams are asked to describe "the ideal girl/woman" or "the ideal boy/man". The teams come together and present their versions of ideal people.
- The group discusses how easy/difficult it is to conform to the "ideals".

##### Game 2: Role play

**PURPOSE:** To raise awareness about discrimination in everyday life.

**DESCRIPTION:**

- The group facilitator suggests a situation involving HIV and Human Rights (For example: "Two friends discuss whether someone with HIV/AIDS should be allowed to work at the school canteen", or "A woman tries to persuade her boyfriend/husband to use condoms").
- Two people are asked to start the role-play, presenting opposite views.
- After a few minutes, the group facilitator/peer educator claps and points to a new person, who has to take the place of one of the "actors".
- The game continues until a range of arguments "for" and "against" have been heard.

[Source: "Stepping Stones", see Resources, below]



### KEY PRACTICAL TIPS FOR PEER EDUCATION AND OTHER GROUP ACTIVITIES

- Where possible, the group leader or facilitator should have some training experience.
- Avoid classroom-style seating arrangements: sitting in a circle usually works well.
- Where possible, use a very brief "energiser" before starting. This can be a song or a fun game to relax and have a laugh together.
- Most group activities work better in small groups (6-20 people)
- Always take time after an activity to encourage participants to share their feelings about it (evaluation).







## RESOURCES :

Please refer to the “**Resources**” in the brochure “Basics to Get Started” for useful web-sites concerning HIV/AIDS issues in general.

**1** • The **IFMSA (International Federation of Medical Students' Associations)** has volunteer advisors who can help with suggestions and information. They can be contacted through Selma Mujezinovic, **e-mail : mujezino@studmed.uio.no**. Or contact the **IFMSA** headquarters at :

• **IFMSA General Secretariat**

c/o World Medical Association  
B.P.63 , 01212 Ferney-Voltaire Cedex France.

Tel : 33 450 404759 Fax : 33 450 405937

**e-mail : gs@ifmsa.org**

**web-site : www.ifmsa.org**

• **IFMSA Director on Reproductive Health including AIDS : scorad@ifmsa.org**

• **IFMSA Director on Refugees and Peace : scorpd@ifmsa.org**

**2** • “*Stepping Stones*”, a manual for facilitators to help run workshops within communities on HIV/AIDS, communication and relationship skills. Used in many countries in all regions. Has an excellent range of games and group activities. Comes with an optional video. Published by **Action Aid**, Hamlyn House, Macdonald Rd, Archway, London. Available for sale from: TALC (Teaching Aids at Low Cost), PO Box 49, St Albans, Herts AL1 5TX, UK. Fax: (+44) 1727 846852; Tel: (+44) 1727 853 869.

**3** • “*School Health Education to Prevent AIDS and STD*” : a practical step-by-step manual including (1) Handbook for curriculum planners; (2) Teachers' Guide, and (3) Students' Activities. Produced jointly by **WHO** and **UNESCO**, it is available without charge and in several languages from WHO. This pack contains many ideas that can be adapted for different age groups. It may be ordered from WHO via the WHO Internet site, or from their Geneva offices:

**WHO**

**web-site : www.who.int**

The World Health Organization Headquarters Office in Geneva,  
Avenue Appia 20, 1211 Geneva 27 Switzerland.

Tel : 41 22 791 21 11 Fax : 41 22 791 3111.

For the addresses of WHO Regional Offices and other WHO Offices see : **www.who.int/regions**

**4** • Manuals for Trainers and Facilitators are available in most regions and languages. For example, in Spanish : “*Dinámicas para la Prevención del VIH/SIDA y ETS*”, LUSIDA, Proyecto de Control de SIDA y ETS, Av. De Mayo 953, Piso 3, Buenos Aires, Argentina. Tel/Fax: (+54) 11 4345-3612; e-mail: lusida@satlink.com.ar

**5** • “*Participatory Learning and Action Notes: Sexual and Reproductive Health*” (PLA Notes No. 37, February 2000), is an excellent compilation of practical information written by community workers and project leaders from different parts of the world. Published by the International Institute for Environment and Development (IIED). IIED may send copies of individual articles for free to local NGOs in developing countries.

Contact them with details of your particular questions or concerns:

**IIED**

3 Endsleigh St, London, WC1H 0DD, United Kingdom,

Fax: + 44 020 7388 2826.

**e-mail : bookshop@iied.org**

**web-site with order details : www.iied.org/bookshop**

**6** • “*UNAIDS, Peer education and HIV/AIDS: Concepts, uses and challenges (Best Practice- Key Material), January 2000*”  
Summary booklet of Best Practices can be viewed at : **www.unaids.org/bestpractice/summary/cyp/index.html**  
For other resources on “ Best practice ”, see also : **www.unaids.org/bestpractice/collection/index.html** ■



# Talking about HIV/AIDS and respecting freedom of thought and religion

**S**ometimes religious or moral beliefs involve codes of sexual and social behaviour that prevent the open discussion of issues related to sexually-transmitted diseases, including HIV/AIDS. Religious beliefs are an important part of the cultural identity of many people. Moreover, freedom of thought and religion is a basic human right, recognised in the Universal Declaration of Human Rights that all states aspire to.

When religions promote love, generosity and acceptance of the dignity of all individuals, they are essential resources to help overcome discrimination and favour tolerance in the context of HIV/AIDS. However one should also keep in mind that:

- Some religious interpretations consider HIV/AIDS a punishment for some kind of improper behaviour.
- Sex education and the promotion of condoms can be controversial.

Today, fears that sex education may undermine family values are largely unfounded. Research has shown, for example, that sex education can help to delay the onset of sexual relations in adolescents and reduce the number of teenage pregnancies.

Here are several examples of how youth organizations together with religious leaders are responding to HIV/AIDS:

## GROUP PRACTICE

### Youth education programme for Islamic Youth in Uganda

**The Islamic Medical Association of Uganda (IMAU) has developed an AIDS education curriculum for children and young people. Students learn about HIV/AIDS transmission, prevention and control. They are shown how to care for AIDS patients and encouraged to help people in their own communities who are suffering from AIDS. Teachers and their assistants organize activities that include music, drama and games. Parents and guardians are encouraged to talk to their children about HIV/AIDS. IMAU gives training to supervisors, who are themselves Imams, County Sheikhs or appointed assistants. They, in turn, train teachers from different mosques. At the beginning, religious leaders did not permit the inclusion of condom education in the curriculum, but later this changed. IMAU tells the following about their co-operation with Islamic leaders:**

*“Perhaps the most difficult issue has been sensitising Islamic*

*leaders to the important role that the condom plays in preventing transmission of the HIV virus. Some religious leaders argued that condom education would promote sex outside marriage, which is against Islamic law....In this dialogue, IMAU stressed that the condom was only being promoted as AIDS protection after the failure of a first and second line of defence: abstaining from sex and having sex only within marriage. IMAU argued that the third line of defence should not be ignored because human beings have their weaknesses, as witnessed by the many cases of sexually-transmitted diseases (STDs). ....Married people who ignore condoms often leave orphans behind and this destroys communities... ...At the end of the dialogue, the Islamic leaders agreed that education on the responsible use of the condom was acceptable within Islamic teachings and necessary to defend communities against AIDS. The condom education component was re-inserted into the education programme in the second year”.*

**Source:** “Islamic Medical Association of Uganda: AIDS education through Imams”, UNAIDS Case Study, UNAIDS, October 1998.



States should promote the wide and ongoing distribution of creative education, training and media programmes explicitly designed to change attitudes of discrimination and stigmatisation associated with HIV/AIDS to understanding and acceptance. Guideline 9, International Guidelines on HIV/AIDS & Human Rights.

**GOOD PRACTICE**

**Argentina: Catholic youth promote solidarity with people living with HIV/AIDS**

A group of Catholic youth wrote the following in a booklet sponsored by the Archbishopric of Buenos Aires, Argentina:

**If a friend has AIDS:**

- **Essential:** make him feel you are near him, take his hand. Tell him you love him.
- **Talk about his solitude:** he is likely to need to talk about it.
- **Visit him as often as you can.** Take along a common friend when possible.
- **Ask him for an outing, if he can still go out.** He will feel safer if he goes accompanied.
- **Show your affection.** If you promise something, don't let him down.
- **Consult him about any activities that you may share.**
- **Do not let him blame himself for his illness.** Encourage him to accept it with hope.
- **Talk about the future.** About tomorrow, next week, next year. Awaken his hope.

Source: Exert from the Spanish original: EL SIDA, DE LOS JOVENES A LOS JOVENES, Editorial Bonum, Maipu 859, 1006 Buenos Aires, tel (ii) 43129209 or 4322 9763.

**INTERVIEW**

**Young students undertake peer education in Islamic and Christian Schools in Lebanon**

Young people from the Lebanese Medical Students' International Committee (LeMSIC) have been working in a peer education programme to reach out to young people in their country. We asked Firas, one of the peer educators, to explain:

**Question - Why did the medical students decide to start a peer education programme?**

«Discussion of sexual behaviour or of sexually-transmitted diseases is difficult in our society. We feel a responsibility to share information with other young people to help break the taboos and raise their awareness».

**Q- Where is your work carried out?**

«We initially gave sessions in secular schools. We are starting to work with traditional Islamic schools, and we have also been asked to run sessions in Christian schools. We are always respectful of the school and religious authorities and always consult them, and we try our best not to by-pass them. We have found that if we

are clear about what we do and our aims, it is possible to find good co-operation. We tell them that we are not there to preach our own version of morality, but simply to share useful information and help young people to make well-informed decisions».

**Q- How do the sessions work?**

«We ask the participants to work in groups of 8. We discuss with them whether specific behaviours carry high, low, or no risk of HIV/AIDS transmission. Then we give them 10 minutes to come up with a 5-minute sketch or play presenting a difficult situation related to HIV/AIDS: We talk about safe sex and do role-play exercises about resisting peer pressure to have sex, learning to accept people living with HIV/AIDS, and dissipating false practices/beliefs. The feedback has been excellent!».

**Q- What advice would you give to others?**

«Religious values are very important in many communities, do not fight them. It is possible to gently break taboos without offending religious beliefs».





## KEY PRACTICAL TIPS FOR YOUNG EDUCATORS

While writing this guide, an informal roundtable on “Working with Religious Communities” was held with young students from different religious backgrounds. We asked them what experiences they could share. They told us:

- “Don’t ‘parachute’ into a religious community if you are not part of it. Try to team up with a youth group of the local religious institutions”.
- “First find out what might be possible, and whether any HIV/AIDS education is already being given within the local religious institutions”.
- “Find out whether there are any religious authorities or leaders who may be open-minded about the importance of HIV/AIDS education and solidarity, and try to get their co-operation and guidance”.
- “It can be counter-productive to criticise or be confrontational”.
- “Remember that the teachings of most religions are in favour of, and not against, tolerance, respect for all God’s children, and caring for the sick”.
- “Present facts and the advice of institutions or persons that are respected”.
- “Anonymous phone help-lines can be very useful in communities where sex is a taboo subject”.

## RESOURCES:

Please refer to the “Resources” in the brochure “Basics to Get Started” for useful web-sites concerning HIV/AIDS issues in general.

- 1 • UNAIDS and IMAU “AIDS Education through Imams” UNAIDS Best Practice case study, Geneva, UNAIDS 1998

Available from UNAIDS via internet: [www.unaids.org/bestpractice/summary/rel/aidsedu.html](http://www.unaids.org/bestpractice/summary/rel/aidsedu.html)

See also [www.unaids.org/bestpractice/digest/index.html](http://www.unaids.org/bestpractice/digest/index.html) for other best practice cases under the topic “Religion”

IMAU (Islamic Medical Association of Uganda)

P.O. Box 2773 Kampala Uganda

Tel: 256 42 251- 443

- 2 • Consultation report: “Journey into Hope: Consultation with Christian Leaders, Development Organisations and UNAIDS on HIV/AIDS Related Issues, 20-23 September 1999, Gaborone, Botswana” Request copies from:

Health Services, Salvation Army International Headquarters,

101 Queen Victoria Street, London EC4P, 4EP, UK

e-mail: [lan-campbell@salvationarmy.org](mailto:lan-campbell@salvationarmy.org) ■







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## ADVOCACY

> **I.** Calling for Government Action.

**SPECIAL FOCUS:**

*Advocacy for equal access to drugs and medical treatment*

> **II.** Legal Action: Protecting Human Rights in the Context of HIV/AIDS

> **III.** Advocacy Beyond Borders: Introduction to the International Human Rights Machinery





# Calling for government action

**Y**oung people, like all other human beings, have the right to life, to development of their potential to the fullest, and to protection from abuse and exploitation, as well as the right of access to information and material aimed at promoting their health and their well-being... These are among the rights listed in the Universal Declaration of Human Rights and other human rights treaties and conventions and also in the International Guidelines on HIV/AIDS and Human Rights (Please refer to Brochure 1 “Basics to get started”, for more information on the contents of the Guidelines).

To what extent are young people aware of their rights? – Do conditions to exercise, claim and defend their rights exist in the community and country where they live? – Do they have places where they can go to make complaints? – When and where the answer to these questions is “no”, young people become more vulnerable to HIV/AIDS. Similarly, when there is no enabling environment, young people living with HIV/AIDS become particularly exposed to discrimination, stigma and isolation.

**Advocacy is a powerful tool to redress abuses and to engage in favour of laws, public policies and community practices that recognise the human rights of young people in the context of HIV/AIDS.**

**Advocacy** means speaking up for your rights and the rights of others. For example, writing a letter to a parliamentarian in support of a national law providing more youth-friendly health services, providing legal assistance to an HIV-positive student who has been denied access to a university because of his/her status, is advocacy.

Advocacy can be conducted individually, and collectively by one or several organizations. It addresses more than human rights, respect and protection at the national level. You can also advocate for initiatives and practices within your community or for private corporate policies, that are compatible with human rights standards.

In recent years, successful advocacy campaigns have been carried out in many countries:

- To obtain better access to treatment and care by people living with HIV/AIDS.
- To stop compulsory HIV testing in the army, civil service, or in schools and universities.
- To abolish laws that criminalise private homosexual acts.
- To obtain public support for needle exchange programmes for injecting drug users.

**It is important to emphasise that advocacy for human rights in the context of HIV/AIDS is not about making charitable concessions to people living with HIV/AIDS, or to vulnerable groups. It is about recognising the rights that already belong to every human being, such as respect for our human dignity and our equal right to participate fully in social and family life.**

When identifying human rights issues for which you will advocate, it is important to keep in mind that states that have signed international human rights treaties, have 3 types of obligations concerning human rights they have recognised:

- Obligation to **respect human rights** (= not to take measures that violate human rights)
- Obligation to **protect/promote human rights** (= take action to prevent - or provide remedy for -violations by others)
- Obligation to **fulfil human rights** (= take positive steps so that rights can be fully exercised, for example through laws and budgetary allocations)





"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 11, International Guidelines on HIV/AIDS and Human Rights.

## EXAMPLES OF HUMAN RIGHTS ADVOCACY ISSUES on HIV/AIDS

(with reference to the International Guidelines on HIV/AIDS and Human Rights)

Examples of states' human rights obligations	State action to respect human rights	State action to protect human rights	State action to fulfil human rights	International Guidelines
<p><b>Example 1:</b> Right to non-discrimination of people living with HIV/AIDS</p>	<p>Refrain from adopting laws authorising compulsory HIV testing of people before marriage, military service, immigration or appointment to government office.</p>	<p>Take measures that sanction employers, hospitals, schools and other institutions from taking discriminatory measures against people living with HIV/AIDS.</p>	<p>Adopt laws that protect the rights of people living with HIV/AIDS to education, employment, health care, etc. Provide legal means (for example, by financing legal aid) to obtain redress when rights are violated.</p>	<p>See Guidelines 5, 7, 8, 9, 10, 11</p>
<p><b>Example 2:</b> Right to health</p>	<p>Authorise condom distribution (or syringe exchange for injecting drug users)</p>	<p>Ensure that health care institutions do not turn people living with HIV/AIDS away and that they provide the best available care. Make confidential HIV-testing easily available.</p>	<p>Establish and finance HIV/AIDS prevention and care programmes, including HIV/AIDS education, condom distribution, needle/syringe exchange, access to treatment and care, access to a good diet for people living with HIV/AIDS, etc.</p>	<p>See Guidelines 3, 4, 6</p>
<p><b>Example 3:</b> Women's and children's right to equality</p>	<p>Refrain from actions that can make women and children more vulnerable. For example: limiting women's right to work, to divorce, to own property; and limiting children's right to information, education, food and shelter.</p>	<p>Adopt laws that prohibit domestic violence and abuse, female circumcision, forced marriages. Take measures to prohibit child abuse and discrimination against AIDS orphans.</p>	<p>Adopt strategies that affirm women's rights to equality before the law: provide funding for women's groups and for assistance to women and children who have been abused within or outside the family, for example.</p>	<p>See Guideline 5</p>



## INTERVIEW

### Interview with a human rights advocate

In Venezuela, ACCSI (Citizen's Action against AIDS/Acción Ciudadana Contra el SIDA), a community organization, campaigned against compulsory HIV-testing of people who wanted to undertake teacher training at the "Universidad Pedagógica Experimental Libertador", a leading centre for university education. After everything else failed, ACCSI took the University to Court and won the case. We asked Edgardo Carrasco and Renate Koch, members of ACCSI, to tell us about their successful action:

**Question: Why did the University impose compulsory testing of applicants?**

The University held the view that it was not worthwhile to invest in the training of individuals who would inevitably die of AIDS, an amazing statement, since all of us have to die sometime. As if that was not enough, the University said in a public statement that people living with HIV/AIDS were "damaged" and could "leave a trail of infected people"

**Q- What was your main argument against this measure?**

Our main argument was based on the right to education, which includes the right to train in a trade or profession of our choice and to develop freely as individuals.

**Q- Why did you decide to take action before the courts and what was the result?**

We first tried every possible means of dialogue with the University. When this failed, and it also became clear that other state authorities would not intervene,

we decided we had no option but to ask the courts of justice to declare the directive issued by the University null and void, and the action was successful.

**Q- What do you think will be the impact of the court ruling?**

The favourable decision of the court has been very well received by the Venezuelan public. However, we must remain vigilant with regard to internal measures that might be taken by other educational establishments...For this reason, ACCSI continues to monitor the situation and to submit complaints whenever necessary. In our view, this is an excellent ruling that should be publicised not only to raise awareness about the duties held by institutions but also to foster a culture of respect for human rights in our communities.

**Q- What advice would you give to people in other countries where compulsory testing is tolerated?**

We believe that it is better to lose than never to have fought at all. We must fight against violations of the rights and dignity of people. If we don't, we turn ourselves into accomplices. The rights enshrined in national and international laws and treaties are not automatically enforced, they are realised through the actions of citizens, and it is these actions that can create a more peaceful world, without violence and with respect for all.

*With thanks to ACCSI, Venezuela, e-mail: [ecarrasco@internet.ve](mailto:ecarrasco@internet.ve); fax: (58 2) 239215 or 2327938 (Please find the complete address in the "Resources" of the brochure "Basics to Get Started")*



## KEY PRACTICAL TIPS FOR ADVOCACY CAMPAIGNS

- Learn about human rights, their contents and existing procedures for their protection. You may contact the human rights commission in your country (if it exists) as well as human rights NGOs.
- Involve people living with HIV/AIDS in the identification of human rights advocacy issues.
- Build coalitions with other organizations and with influential people.
- Have a media strategy - involve someone who knows how to get press coverage.
- Choose your timing well: if you are targeting Parliament or Congress, get advice about the best time to lobby.
- When addressing government officials in petitions, letters or meetings, remember that brief, clear statements describing the specific action, that you want to be taken, are more effective than long documents.





## SPECIAL FOCUS: Advocacy for equal access to drugs and medical treatment

### THE CHALLENGE

Improving access to drugs and medical treatment for people living with HIV/AIDS is perhaps the most difficult and urgent issue facing the world community today in the context of HIV/AIDS and human rights. The reality is stark in many countries. People living with HIV/AIDS often cannot access even the most basic medication to treat secondary conditions (such as tuberculosis) or to relieve pain, even though some of these drugs are very common and cheap in other parts of the world. An even more challenging problem concerns the expensive but very important anti retroviral drugs, which limit the damage that HIV does to the immune system and therefore can make it possible for people living with HIV/AIDS to lead relatively full lives for many years. All of this undermines fundamental rights: the right to health and the right to life of people living with HIV/AIDS.

**A basic healthcare package for people living with HIV/AIDS** includes social support, counselling, a good diet, the treatment of secondary conditions, pain relief, and access to anti-retroviral drugs.

The classes of drugs most important to people living with HIV/AIDS are:

- *anti-infectives* to treat or prevent opportunistic infections;
- *anti-cancer drugs* to treat tumours such as Kaposi sarcoma and lymphoma;
- *palliative care drugs* to relieve pain and discomfort;
- *anti-retroviral drugs*, to suppress the HIV virus and maintain the ability of the immune system to resist disease.

Access to anti-retrovirals is currently the most controversial issue: these drugs can greatly improve the health and life expectation of people living with HIV/AIDS. At the same time, they are expensive and their price can be particularly high in developing countries. The result is that they are only accessible to a minority of people living with HIV/AIDS.

It is important to keep in mind that the problem of access to drugs and treatment is not limited to access to anti-retrovirals. It also includes access to more basic medicines, such as those needed to treat opportunistic infections and painkillers. The lack of access to treatment is a human rights violation for every human being.

### ACCESS TO HIV/AIDS MEDICATION AND HUMAN RIGHTS

A resolution on "Access to medication in the context of pandemics such as HIV/AIDS was adopted by the UN Commission on Human Rights (\*)

#### The UN Commission on Human Rights:

- Recognises that access to medication in the context of pandemics such as HIV/AIDS is an element fundamental to achieving full realisation of the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.
- Calls upon states to pursue policies that would promote the availability in sufficient quantities, accessibility to all without discrimination and the scientific appropriateness and quality of pharmaceuticals or medical technologies used to treat pandemics such as HIV/AIDS.
- Encourages states to adopt measures to safeguard access to preventive, curative or palliative pharmaceuticals or medical technologies from any limitations by third parties.

(\*) Resolution E/CN.4/RES/2001/33, UN Commission on Human Rights 57th Session, 2001

"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" Guideline 6, International Guidelines on HIV/AIDS and Human Rights.





## **Brazil: National production of generic drugs to lower the cost of universal access to treatment**

In Brazil, the Government has a policy of universal access to antiretroviral drugs which currently benefits nearly all AIDS patients in the country (about 85,000). The introduction of combination antiretroviral therapy nearly halved the annual number of AIDS deaths between 1996 and 1999, and reduced the incidence of opportunistic infections by 60-80% over the same period.

The universal access programme would not have been possible without significant decreases in the cost of anti-retroviral drugs. The Government decided to start local manufacture of drugs that were not patent-protected, and for which it had the know-how and infrastructure. Local production, combined with bulk purchases of imported anti-retrovirals, led to significant decreases in the programme's drug costs.

The programme's annual drug costs were approximately US\$ 339 million in 1999. Between 1997 and 1999, approximately 146,000 AIDS-related hospitalisations were averted, resulting in savings of approximately US\$ 289 million: this has partly offset the high cost of antiretroviral therapy.

Source: Report on the Global HIV/AIDS Epidemic, UNAIDS, June 2000.

### **HOW TO ADVOCATE FOR EQUAL ACCESS TO DRUGS AND TREATMENT?**

Resolutions and decisions of important bodies such as the UN Commission on Human Rights are important tools for educating and lobbying governments to advocate equal access to drugs and treatment. Very specific and different strategies to reduce the cost of drugs, to improve health services and infrastructure or simply to call on governments' obligation to implement the right to health, have been developed throughout the world. Some have already succeeded in improving access to treatment for people living with HIV/AIDS... Here are some examples:

#### **Example 1: Compulsory licensing**

Anti-retrovirals are new: therefore, they are still under patent held by pharmaceutical companies that have researched, developed and are commercialising these drugs. International patent regulations such as the "Trade Related Aspects of Intellectual Property Rights" (TRIPS) allow, under exceptional circumstances, governments to license the production of a drug in their country without the authorisation of the patent holder, so that generic equivalents can be made available. In this context, the last "Declaration on the TRIPS Agreement and Public Health" issued by the World Trade Organization Ministerial Conference in Doha, 14 November 2001, makes it explicit that "public health crises, including those relating to HIV/AIDS, tuberculosis, malaria and other epidemics, can represent a national emergency or other circumstances of extreme urgency" for issuing a compulsory license. This strategy can create a supply of less expensive drugs, and bring down the price of proprietary drugs through competition. As a result, drugs and anti-retrovirals in particular become accessible to a larger number of people living with HIV/AIDS. The main argument presented against compulsory licensing is that if patent protection is waived, pharmaceutical companies, that invest in research and development, will have less incentive to develop new drugs or vaccines. The pharmaceutical industry also argues that generic drugs can be of inferior quality, and may increase the risk of ineffective counterfeit products being sold in the black market.

#### **Example 2: Parallel importing**

This strategy involves buying either a generic or a proprietary drug from another country where the price is lower, rather than directly from the manufacturer. This practice takes advantage of the fact that pharmaceutical companies charge lower prices in some countries than in others, depending on market and other conditions.

In this case there have also been pressures to stop the practice, which is seen to undermine the established distribution mechanisms and pricing strategies of the manufacturers.

#### **Example 3: Preferential pricing**

This strategy involves reducing drug prices charged to poorer countries. At the time of writing, in accelerating access price, reductions of 85 to 95% were obtained for anti-retroviral drugs in 10 African countries. (For a list of countries which have expressed interest in joining the Accelerating Access Initiative, please see: [www.unaids.org/acc\\_access/AAcountries1101.doc](http://www.unaids.org/acc_access/AAcountries1101.doc)). However, even at this low price level, the drugs remain out of reach for many clients and governments. So further work is needed to continue to decrease prices, on one hand and to finance them through international solidarity, on the other hand. This is one of the purposes of the Global Fund to fight AIDS, Tuberculosis and Malaria which was endorsed by the Declaration of Commitment, UN General Assembly Special Session on HIV/AIDS, in June 2001.



#### Example 4: Improving healthcare infrastructures

In many countries, the inadequacy of existing healthcare infrastructures makes it difficult to distribute and dispense drugs safely and regularly, even if low prices or other facilities are made available. A circular argument appears to have developed on this point: while some manufacturers argue that the main obstacle to access to drugs is the failure of governments to develop adequate infrastructures, governments with low budgets argue that spending on additional infrastructures is not productive if medicines are not available.

### Senegal: Health System and Infrastructures to Support Antiretroviral Treatment - Pilot Project

In Dakar (Senegal), a pilot project is being implemented that, in the view of the organizers, proves that it is possible for developing countries to set up the systems and infrastructures needed to support anti-retroviral treatment for AIDS patients.

A government grant has provided enough funding to treat 70 patients, at a cost of about US\$ 460 per person per month. The programme is led by a committee that includes representatives of government services, independent medical and psychiatric specialists, social services, lawyers and representatives of associations of people living with HIV/AIDS. Patients make a financial contribution to the treatment, according to their means. The numbers included in the programme are deliberately small, because it is essential

to ensure that funds will be sufficient to continue the treatment. "We have to continually be sure that the mechanisms are working, through efficient financing, drug management and biological, clinical and psychological follow-up of the patients.", says Salif Sow, a national committee member. Grants from international sources have been used to build a laboratory and to give free viral load and CD4 count tests. An evaluation of the programme has shown that "the wheels were well greased and demonstrated that an African country can start a programme of this type and keep it going. If it works in Dakar, we now have to try to expand the sites to the interior of the country". There are plans to set up a foundation to attract further funds to expand the programme.

Source: "Beyond our Means?", The Panos Institute, 9 White Lion Street, London N1 9PD, 2000. e-mail [aids@panoslondon.org.uk](mailto:aids@panoslondon.org.uk)

"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"

Guideline 6, International Guidelines on HIV/AIDS and Human Rights.

#### Example 5: Calling on states' obligation to implement the right to health

This strategy is based on the assumption that universal access to treatment - including access to anti-retrovirals - for people living with HIV/AIDS, is an element of the right to life and health. As a result, states that recognise the right to health in their international constitution and laws, and/or have ratified international human rights instruments that mention the right to health, have the obligation to take the necessary measures for the provision of universal access to treatment in their country.

This strategy, focused on legal action in courts, has been successfully used in several countries in Central and Latin America, where the rate of HIV-prevalence remains moderate. It is worth noting that this strategy has never been used as such in countries with high HIV-prevalence.



## Argentina: Courts of justice uphold the right to healthcare

In Argentina, a network of about 70 organizations working on HIV/AIDS carried out years of vigorous campaigning calling on the health authorities to ensure the regular supply of drugs to people living with HIV/AIDS. In 1996, confronted with large numbers of patients who were left without treatment, and others who had to interrupt their therapy, six organizations in the network decided to take the government to court. In June 2000, the Supreme Court confirmed a decision of the lower courts that orders the Ministry of Health and Social Welfare to comply with its obligation to provide healthcare for all the population, including comprehensive medical attention for AIDS patients, comprising the regular supply of appropriate drugs. Several other Latin American countries have introduced a legal right to treatment for AIDS patients, including Brazil, Colombia, Costa Rica, Uruguay and Venezuela.

Source: Report on the Global HIV/AIDS Epidemic, UNAIDS, June 2000.

**Other measures** that can help to improve the situation, include donations from pharmaceutical companies, subsidised loans from international financial institutions such as the World Bank, grants from development aid agencies, the removal of import duties by interested governments, etc.



### KEY PRACTICAL TIPS FOR TAKING ACTION ON ACCESS TO TREATMENT

- Seek precise and scientifically correct information on existing needs in your country regarding access to treatment and, in consultation with people living with HIV/AIDS and other interested organizations, decide on the best strategy to adopt (cf. above) to defend equal access to treatment.
- Ask advice from lawyers, medical professionals, etc... to master the technical aspects of the access to treatment debate. (See Resources, below).
- Take into account your government's current position, and any negotiations it may be holding with pharmaceutical companies. If necessary, ask your government to state its policies and plans.
- If the absence of health infrastructures is a major problem in your country, lobby your government to support a pilot project (See Senegal example, p.7)
- Consider joining other groups that are lobbying for equal access to treatment at the international level (See Resources, below).

### RESOURCES :

Please refer to the "**Resources**" in the brochure "Basics to Get Started" for useful web-sites concerning HIV/AIDS issues in general.

- 1 • "*Handbook for Legislators on HIV/AIDS, Law and Human Rights*" - Clear and comprehensive guide to a wide range of measures that governments need to implement to comply with the recommendations in the International Guidelines on HIV/AIDS and Human Rights. Jointly published by the Inter-Parliamentary Union (IPU) and UNAIDS.

Available from **UNAIDS**, 20 Avenue Appia, CH-1211 Geneva 27, Switzerland.

**e-mail: [unaids@unaids.org](mailto:unaids@unaids.org)**

**web-site: [www.unaids.org](http://www.unaids.org)**

- 2 • "*An Advocate's Guide to the International Guidelines on HIV/AIDS and Human Rights*", ICASO.

ICASO has regional offices in Africa, Asia, Europe and Latin America. (Please refer to the "Resources" of the brochure «Basics to Get Started» for details).

**ICASO** (International Council of AIDS Service Organizations),

399 Church St, 4th Floor, Toronto, Canada M5B 2J6.

Tel: (1 416)340-2437, **e-mail: [info@icaso.org](mailto:info@icaso.org)**

**web-site: [www.icaso.org](http://www.icaso.org)**

- 3 • An up-to-date list of the international human rights treaties subscribed by each country is available from the Office of the UN High Commissioner for Human Rights. The list is also available from its web-site.





The Office of the High Commissioner for Human Rights,  
OHCHR-UNOG 8-14 Avenue de la Paix 1211 Geneva 10, Switzerland  
Tel: 41 22 917 9000 Fax: 41 22 917 9016. **web-site : [www.unhchr.ch](http://www.unhchr.ch)**

- 4 • UNESCO publication "Human Rights – Major International Instruments status as at 31 May 2001" is available free of charge from:

**Division of Human Rights, Democracy, Peace and Tolerance**  
**Sector of Social Science and Human Sciences**  
UNESCO 7, Place de Fontenoy, 75352 Paris 07 SP, France  
Fax: 33 1 45 68 57 26 and also via internet : **[www.unesco.org/human\\_rights/index.htm](http://www.unesco.org/human_rights/index.htm)**

### SPECIAL FOCUS ON ACCESS TO TREATMENT

- 1 • "Compulsory Licensing and Parallel Importing", August 1999 - a briefing paper in English, French and Spanish, produced by ICASO (International Council of AIDS Service Organizations), 399 Church St, Toronto, ON, Canada M5B 2J6, Tel: (+1-416) 340 2439, **e-mail: [info@icaso.org](mailto:info@icaso.org)**  
**web-site: [www.icaso.org](http://www.icaso.org)**
- 2 • "Beyond our Means ? : The Cost of Treating HIV/AIDS in the Developing World", 2000. PANOS Institute, 9 White Lion St, London N1 9PD, United Kingdom, Tel (+44) 20 7278 0345, **e-mail: [aids@panoslondon.org.uk](mailto:aids@panoslondon.org.uk)**  
**web-site: [www.panos.org.uk](http://www.panos.org.uk)**
- 3 • **Health Action International**: an international network of organizations involved in health and pharmaceutical issues, which has been very active in international advocacy.  
**Health Action International**  
c/o HAI Europe, Jacob van Lennepkade 334-T, 1053 NJ Amsterdam, Netherlands.  
Tel: (+31) 20 683 3684, **web-site: [www.haiweb.org](http://www.haiweb.org)**
- 4 • **[www.aidsmap.com](http://www.aidsmap.com)** Internet site with extensive information about treatment for HIV/AIDS
- 5 • **UNAIDS** (Joint United Nations Programme on HIV/AIDS): UNAIDS is involved in negotiations with pharmaceutical companies. Publishes regular Technical Updates on treatment.  
**UNAIDS** 20 avenue Appia, CH-1211 Geneva 27, Switzerland.  
Tel: (+41) 22 791 4651, **e-mail: [unaids@unaids.org](mailto:unaids@unaids.org)**  
**web-site: [www.unaids.org](http://www.unaids.org)**
- 6 • **WHO** (World Health Organization): UN Agency that promotes health. It has drawn up a Model List of Essential Drugs that provide the most cost-effective treatment available for the most prevalent infectious and chronic diseases. National governments are encouraged to adopt their own lists. WHO has also published Guidance Modules on Antiretroviral Treatments.  
**WHO**, CH-1211 Geneva 27, Switzerland.  
Tel: (+41) 22 791 2476. **web-site: [www.who.int](http://www.who.int)**
- 7 • **UNICEF** Report "Improving access to HIV/AIDS drugs" can be obtained via internet : **[www.unicef.org/hivdrugs/](http://www.unicef.org/hivdrugs/)**
- 8 • **Médécins sans Frontières** - (MSF) is an international humanitarian aid organization that provides emergency medical assistance to populations in danger in more than 80 countries. In carrying out humanitarian assistance, MSF seeks also to raise awareness of crisis situations. MSF runs a campaign for Access to Essential Medicines in the context of HIV/AIDS.  
**MSF**, 8 Rue Saint-Sabin 75011 Paris, France  
Tel: 33 1 40 21 29 29 Fax: 33 1 48 06 68 68 **e-mail : [office@paris.msf.org](mailto:office@paris.msf.org)**  
**web-site : [www.msf.org](http://www.msf.org)** ■

"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"

Guideline 6, International Guidelines on HIV/AIDS and Human Rights.



# Legal action: Protecting human rights in the context of HIV/AIDS

**S**eeing justice is a human right in itself, as stated in article 8 of the Universal Declaration of Human Rights: “Everybody has the right to an effective remedy by the competent tribunals for acts violating the fundamental rights granted him (or her) by the constitution or by law”. Seeking justice to obtain remedy for specific violations and abuses of human rights in the context of HIV/AIDS is also an important way to advocate against discrimination affecting people living with HIV/AIDS and to enforce laws that are key to HIV prevention, such as regulations about the safety of blood transfusions.

When a case is won, it may benefit a large number of people living with HIV/AIDS and help to strengthen positive attitudes towards them. Courts of justice exist to remedy injustices, to interpret and implement national law, and to ensure observance of international norms that have been adopted by the country. You may have the feeling that the judicial system is inaccessible to most vulnerable groups and too procedural, and that it is therefore incapable of providing timely and adequate responses to injustices caused by human rights abuses in the context of HIV/AIDS. Here are some concrete examples of how courts of justice enforce human rights, thus helping to improve daily life for people living with HIV/AIDS and strengthening HIV-prevention.

## When justice makes human rights become a reality...

- In Venezuela a civil action was brought on behalf of children living with HIV/AIDS and, as a result, all children are now entitled to receive combination therapy.
- In the United States, the Supreme Court upheld a claim of discrimination brought by a woman against a dentist who had refused her dental treatment on account of her HIV status. The courts rejected the dentist's argument that treating her would pose a direct threat to his health.
- In South Africa, in the case of ‘A’ v South African Airways (SAA), the SAA made a settlement offer of R 100.000 to A and also agreed to pay all legal costs for the case. The SAA unconditionally admitted that the exclusion of A from the position of cabin attendant on the grounds of his HIV status was unjustified. Implicit in SAA's admission was that SAA should have obtained A's informed consent in conducting the HIV test and should have given him pre and post-test counselling in conducting the HIV test.
- In Australia, a tribunal ruled in favour of an HIV-positive football player who complained after his club refused to register as a player because he was HIV-positive. The tribunal said that the very low risk of transmitting HIV to other players if reasonable precautions were taken meant that the club's decision was not justified.

Source: Canadian HIV/AIDS Policy and Law Newsletter, Vol. 4, No.4, Summer 99

**Legal action** is a powerful tool to advocate for more effective human rights protection by courts. It is about **facilitating access to justice** for all, and in particular for people with low income and people who may be socially or culturally excluded in your community. It is also about **promoting equal justice**, meaning law enforcement based on the protection of human rights for all.

Legal action in the context of HIV/AIDS includes different kinds of help depending on the legal problems experienced by people living with HIV/AIDS and vulnerable groups in your community. This includes, a wide range of possible actions such as:

- Information and advice to people whose rights are threatened, on laws protecting human rights in the context of HIV/AIDS,
- The services of a professional lawyer to defend a case in a justice court (= legal representation),
- Preparation of a “test case” to obtain a ruling by a national justice court, or a regional human rights court (cf. Chapter 3 of this brochure) on a key issue concerning human rights in the context of HIV/AIDS
- Advocacy to change laws in your country that fall short of human rights standards, and to implement the International Guidelines on HIV/AIDS and Human Rights.



Here are some examples of concrete legal problems in the context of HIV/AIDS which exist in various parts of the world:

#### TAKING ACTION

### Key legal problems to be addressed...

- Employers require HIV-testing of candidates before appointing them to a job.
- The right to confidentiality when announcing HIV-positive status, is not properly protected.
- HIV/AIDS-positive women are deprived of property or maintenance, if abandoned by their husbands.
- HIV-testing without consent is permitted.
- People who are HIV-positive are forbidden to marry.
- HIV-positive people are refused admittance to hospital.
- There is no sufficient protection of rape victims, and of victims of domestic violence and sexual abuse within or outside the family.
- There is prohibition of syringe exchange services for injecting drug users.
- There is impunity for traffickers and others involved in the commercial sexual exploitation of children or women.
- Hospitals/clinics refuse to treat people living with HIV/AIDS.

**Providing easy access to legal information and advice** to young people is a legal aid service in which youth organizations have a key role to play. In many universities, legal information centres are set up by students and provide services to people within and outside the university. Linking up with professional organizations of lawyers is essential, so that legal information can be easily followed-up by legal advice and representation, if needed. Support campaigns to change laws that do not conform with international human rights standards is another area of legal action in which youth organizations have a lot to contribute (cf. Brochure 2: Public awareness campaigns to fight discrimination in your community)



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 utilise means of protection in addition to the courts, such as offices of ministries of justice, ombudspersons, health complaint units and human rights commissions. Guideline 7, International Guidelines on HIV-AIDS and Human Rights.



## GOOD PRACTICE

### Example : Legal information and advice in India...

The Lawyers Collective HIV/AIDS Unit in Mumbai and New Delhi (India) provides legal aid and advice to people living with HIV/AIDS. They have produced a small but very useful leaflet that can be easily distributed to inform people about their rights.

The "Know Your Rights" leaflet explains:

*"Your Basic Rights: In India, all people are entitled to basic or fundamental rights in the eyes of the law. It does not matter what the religion, race, sex, or place of birth of that person is. Neither do these rights change just because an individual is affected by HIV"*

The leaflet provides a simply written summary of the practical implications of the Right to Informed Consent, Right to Confidentiality and the Right to Non-discrimination.

It also encourages readers to use the power of the law if their rights are abused: *"So whether it's something as simple as using a public [drinking] well or something more serious like denial of housing, remember you have the right to be treated equally. And you have the support of the legal system to ensure it"*

Source: Lawyers Collective HIV/AIDS Unit, 7/10 Botawalla Building, 2nd. Floor, Horniman Circle, Fort, Mumbai - 400 023 India. Tel: (22) 267 6213/9, e-mail: [aidslaw@vsnl.com](mailto:aidslaw@vsnl.com).



## KEY PRACTICAL TIPS FOR LEGAL ACTION

- Consult with vulnerable groups and people living with HIV/AIDS to know their legal problems.
- Get informed about legal rights and laws in your country concerning HIV/AIDS.
- Associate with law students and/or youth advocacy groups to learn about judicial procedures and public legal services that support equal access to justice.
- Link-up with professional organizations of lawyers and judges, as well as medical personnel and discuss with them opportunities for legal action.

## RESOURCES :

Please refer to the "Resources" in the brochure "Basics to Get Started" for useful web-sites concerning HIV/AIDS issues in general.

### 1 • Canadian HIV/AIDS Legal Network

417, rue Saint-Pierre, bureau 408 Montreal QC H2Y 2M4 Canada  
Tel: 514 397 6828 fax: 514 397 8570 **web-site: [www.aidslaw.ca](http://www.aidslaw.ca)**

### 2 • Lawyers Collective HIV/AIDS Unit

7/10 Botawalla Building, 2nd. Floor, Horniman Circle, Fort, Mumbai - 400 023.  
Tel: India (22) 267 6213/9, **e-mail: [aidslaw@vsnl.com](mailto:aidslaw@vsnl.com)**.

### 3 • The AIDS Law Project , South Africa

Centre for Applied Legal Studies, Private B3 University of the Witwatersrand Johannesburg, 2050 South Africa  
Tel: 27 11 403 69 18 Fax: 27 11 403 23 41  
**web-site: [www.hri.ca/partners/alp](http://www.hri.ca/partners/alp)**

### 4 • ICASO (International Council of AIDS Service Organizations)

399 Church St, 4th Floor, Toronto, Canada M5B 2J6.  
Tel: (1 416)340-2437, **e-mail: [info@icaso.org](mailto:info@icaso.org)**  
**web-site: [www.icaso.org](http://www.icaso.org)**

(Please see the "Resources" in the brochure "Basics to Get Started" for ICASO regional offices)

### 5 • ELSA (European Law Students Association)

Director for Human Rights –ELSA International: Cornelia Schneider. You can write to her at: **[elsa\\_hr@hotmail.com](mailto:elsa_hr@hotmail.com)**  
**ELSA International,**  
239, boulevard Général Jacques B - 1050 Brussels, Belgium  
Tel: 32 2 646 26 26 Fax: 32 2 646 29 23 **e-mail: [elsa@brutele.be](mailto:elsa@brutele.be)**  
**web-site: [www.this.is/elsa](http://www.this.is/elsa)** ■





# Advocacy beyond borders: Introduction to the international human rights machinery

**I**nternational advocacy against HIV-based human rights abuses and discrimination may seem remote from realities at the grass roots level and therefore not appear to be a priority area for many youth organizations... However, on closer examination, international governmental organizations (IGOs) – including the United Nations System offer a number of concrete means to advocate for improved respect for human rights in the context of HIV/AIDS. They can:

- **Develop and articulate human rights norms relating to HIV/AIDS.** In 1991, the UN Human Rights Committee discussed the question of laws that make homosexuality a punishable offence. The Committee issued a statement concluding 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...”
- **Hold governments accountable for HIV-related human rights abuses, through human rights monitoring and protection mechanisms.** For example, the UN Human Rights Commission assumes such a monitoring role: it has asked states to report back to the Commission by 2001, on the implementation of the International Guidelines on Human Rights and HIV/AIDS. Another example, this one at regional level, is the Inter-American Human Rights Court and the European Court of Human Rights which through judicial rulings can protect human rights of people living with HIV/AIDS.
- **Advocate for state compliance under the human rights conventions signed by the country.** For example, when a government signs or ratifies the Convention on the Rights of the Child, it is obliged to report back to the United Nations on a regular basis on the implementation of the Convention. The Committee of the Rights of the Child examines these reports.

The international human rights machinery thus presents many opportunities for action by non-governmental organizations. To get effectively involved, the first step is to learn more about those mechanisms and institutions where human rights and HIV/AIDS are discussed at the international level:



States should co-operate 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.

Guideline 12, International Guidelines on HIV/AIDS and Human Rights.



## The International Human Rights Machinery and HIV/AIDS:

### 1 • Are states obliged to respect and promote human rights?

When human rights are recognised by a convention or treaty, YES. States have political and legal obligations of compliance. There is a wide range of human rights related UN treaties or conventions, as well as certain regional conventions; these all create obligations for those countries that have signed or ratified them. Reporting, monitoring and protection mechanisms exist to make Governments accountable to civil society in their country and abroad.

### 2 • Is there any international convention or treaty on human rights and HIV/AIDS?

No – there is no international convention or treaty specifically addressing human rights and HIV/AIDS. But, there are many treaties and conventions that contain human rights principles relevant to HIV/AIDS. These include for example the International Covenant on Civil and Political Rights, the International Covenant on Economic, Social and Cultural Rights, the Convention on the Elimination of All Forms of Discrimination against Women and the Convention on the Rights of the Child. Internationally recognised human rights principles relevant to HIV/AIDS include the right to non-discrimination and equality before law, the right to life

and to health, the right to information and to freedom of expression, the right to marry and raise a family, the right to work to an adequate living standard and to social security, the right to share in scientific advancement and its benefits, etc.

The International Guidelines on HIV/AIDS and Human Rights, issued by UNAIDS and the UN Office of the High Commissioner for Human Rights provide recommendations to states on how to apply internationally recognised human rights in the context of HIV/AIDS.

### 3 • What can the UN or other international governmental organizations do when governments fail to comply with human rights obligations?

- Official investigation of alleged human rights abuses
- Recommendations to individual governments
- Technical assistance to governments, for example to review laws or practices
- Rulings on specific violations of human rights by regional courts (Two such courts exist at present : the Inter-American Court of Human Rights and the European Court of Human Rights)
- Publication of reports about the human rights situation in particular countries, or with regard to specific groups (for example, women, children, indigenous people, etc.), or themes (child





prostitution, extreme poverty, migrants, right to education, etc.) of relevance to HIV/AIDS.

#### **4 • Which UN institutions/bodies are dealing specifically with HIV/AIDS related human rights abuses?**

The UN Office of the High Commissioner on Human Rights is mandated to deal with the human rights of all, including the rights of people living with HIV/AIDS. Furthermore, UN human rights bodies such as the UN Commission of Human Rights, the Human Rights Committee, the Committee on Economic Social and Cultural Rights, the Committee on the Elimination of Discrimination against Women and the Committee on the Rights of the Child are increasingly dealing with HIV/AIDS related human rights abuses. Non-governmental organizations can contact and provide input to the work of these bodies in various ways (cf. “Getting involved in international advocacy” – p.16)

#### **5 • Can individual cases of alleged HIV/AIDS-based human rights violations be taken to an international court ?**

There is a regional court functioning at the moment which hear individual cases from member countries of the Council of Europe: the European Court of Human Rights. They can hear cases of alleged breach of the European Convention on Human Rights.

States should co-operate 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.

Guideline 12, International Guidelines on HIV/AIDS and Human Rights.



## GETTING INVOLVED IN INTERNATIONAL ADVOCACY...

Here are some examples of how your organization can advocate for human rights in the context of HIV/AIDS, at the international level:

■ **Your organization, and sometimes individuals can send information to inter-governmental bodies that investigate human rights abuses.** If you want to submit information to an inter-governmental agency, you will find it useful to work together with a human rights organization in your country. They will have information about your country's international obligations and experience working with the United Nations and other inter-governmental organizations.

Some of the UN bodies or programmes that are particularly interested in receiving information about human rights and HIV/AIDS are:

- The **UN Human Rights Commission**, which looks at general issues, rather than individual cases, and some of its special investigating experts, including the Special Rapporteur on Violence Against Women, the Special Rapporteur on Human Rights and Extreme Poverty, the Special Rapporteur on the Right to Education, and others.
- The **Committee on the Elimination of Discrimination Against Women**, a treaty-based body that oversees the implementation of the Convention for the Elimination of All Forms of Discrimination Against Women.
- The **Committee on the Rights of the Child**, a treaty-based body established to monitor the implementation of the Convention on the Rights of the Child.

(You will find contact details for these bodies in the "Resources" of this section.)

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## "THE PROTECTION OF HUMAN RIGHTS IN THE CONTEXT OF HIV/AIDS" DISCUSSED BY THE UN COMMISSION ON HUMAN RIGHTS

The UN Commission on Human Rights has repeatedly discussed and given clear messages regarding the importance of promoting and protecting human rights in the context of HIV/AIDS. (\*)

**The Commission calls on governments, the UN and NGOs to :**

- Take all necessary measures for the protection of HIV/AIDS related human rights, including ensuring that their laws, policies and practices respect human rights in the context of HIV/AIDS.
- Assist developing countries, and in particular the least developed countries and those in Africa, in their efforts to prevent the spread of the epidemic and alleviate and control the impact of HIV/AIDS on the human rights of their populations and care for those affected.

(\*) Resolutions : E/CN.4/RES/1997/33 UN Commission on Human Rights 53rd Session, 1997; E/CN.4/RES/1999/49 UN Commission on Human Rights 55th Session, 1999; E/CN.4/RES/2001/51 UN Commission on Human Rights 57th Session, 2001.

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■ Find out what steps your government is taking to implement the **International Guidelines on Human Rights and HIV/AIDS** and make your own comments on what your organization believes is needed in your country. Governments' reports to UN bodies are normally available to the public. This type of action is more productive and effective if done jointly with other organizations in your country working on HIV/AIDS and human rights. For further information, contact the Office of the UN High Commissioner for Human Rights and/or UNAIDS. (Please find contact details under "Resources")

■ Some non-governmental organizations (NGOs) are able to participate as observers in sessions of the **UN Human Rights Commission or its subsidiary body, the Subcommission on the Prevention of Discrimination and Protection of Minorities** and make oral statements. This is a powerful way of presenting a view to the international community. The NGOs who can attend have a "consultative status" such as the International Federation of Medical Students' Association (IFMSA). Currently, there are 2012 NGOs with consultative status. (For further information on applying for "consultative status" with the UN Economic and Social Council (ECOSOC) and for the complete list of NGOs who have "consultative status", please see "questions" at : [www.un.org/esa/coordination/ngo/](http://www.un.org/esa/coordination/ngo/) - You may also find a complete list of the Youth NGOs working with UN at the UN [web-site : www.un.org/esa/socdev/unyin/links.htm](http://www.un.org/esa/socdev/unyin/links.htm))

■ Individual cases of alleged human rights abuses may be admitted and heard by a regional court, if there is one in your region, and if all domestic (national) remedies have been exhausted. Individual complaints may be submitted to the **UN Human Rights Committee** under a special mechanism set up in the Optional Protocol to the Covenant on Civil and Political Rights. Providing legal advice to formulate complaints can be a complex process: it is therefore a good idea to establish links with human rights organizations in your country or abroad that are familiar with the international human rights machinery.



## An HIV/AIDS-related case before the European Court of Human Rights...

The European Court of Human Rights prevented the United Kingdom from deporting a foreign visitor with AIDS to his country of origin. The man had been convicted of drug offences and had been diagnosed with AIDS while serving his sentence. He was due to be deported after release from prison. The European Court, however, accepted that the man was terminally ill, and that his removal to a place where adequate treatment was not available would shorten his life and deprive him of his right to life. His death

would not only be accelerated, it would come about in inhuman and degrading conditions, in violation of the right not to be subjected to inhuman or degrading treatment or punishment. The Court found that Article 3 prohibits in absolute terms torture or inhuman or degrading treatment or punishment, and that its guarantees apply irrespective of the reprehensible nature of the conduct of the person in question.

*D v The United Kingdom (case number 146/1996/767/964).*

*From an article by Hseuh Mei Tan in the Australian HIV/AIDS Legal Link 1997; 8(2): 18-19.*

States should co-operate 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.

Guideline 12, International Guidelines on HIV/AIDS and Human Rights.

### RESOURCES:

Please refer to the “Resources” in the brochure “Basics to Get Started” for useful web-sites concerning HIV/AIDS issues in general.

- 1 • For a more detailed explanation of the UN Human Rights mechanism relevant to HIV/AIDS, see “The UNAIDS Guide to the United Nations Human Rights Machinery”, available at no cost from:

#### UNAIDS,

20 Ave Appia, CH-1211 Geneva 27, Switzerland.

Tel: (+4122) 791 4651; Fax (+4122) 791 4165,

Alternatively, try the UN office in your country.

- 2 • For advice on accessing the UN Human Rights Machinery or submitting complaints to the UN please contact:

#### UN Office of the High Commissioner for Human Rights (OHCHR),

8-14 Avenue de la Paix, CH-1211 Geneva 10, Switzerland.

Tel: 41 22 917 90 00.

In particular: • **Human Rights Committee**

c/o OHCHR – UNOG, 8-14 Avenue de la Paix, CH- 1211 Geneva 10, Switzerland

Tel: 41 22 917 90 00 Fax: 41 22 917 90 22

#### • **Committee on the Elimination of Discrimination against Women**

c/o OHCHR – UNOG, 8-14 Avenue de la Paix, CH-1211 Geneva 10, Switzerland

Tel: 41 22 917 90 00 Fax: 41 22 917 90 06

or contact:

#### **United Nations Division for the Advancement of Women,**

2 UN Plaza, DC2-12th Floor New York, NY, 10017 USA

Fax: 1 212 963 34 63 e-mail: [daw@un.org](mailto:daw@un.org)

web-site: [www.un.org/womenwatch/daw](http://www.un.org/womenwatch/daw)

#### • **Committee on the Rights of the Child**

c/o OHCHR – UNOG, 8-14 Avenue de la Paix, CH-1211 Geneva 10, Switzerland

Tel: 41 22 917 90 00 Fax: 41 22 917 90 10

Model questionnaires for communications/complaints are provided by OHCHR at:

[www.unhcr.ch/html/menu2/8/question.htm](http://www.unhcr.ch/html/menu2/8/question.htm)



### 3 • European Court of Human Rights

Cour Européenne des Droits de l'Homme, Conseil de l' Europe, F - 67075 Strasbourg-Cedex

Tel: 33 (0)3 88 41 20 18 Fax: 33 (0)3 88 41 27 30

**web-site : [www.echr.coe.int](http://www.echr.coe.int)**

### 4 • Inter-American Court of Human Rights

Apdo 6906-1000 San José, Costa Rica

Tel: 234-0581, 225-3333 Fax (506) 234-0584

### 5 • Some international NGOs work on international and national legal issues, including litigation:

- **ICASO** (International Council of AIDS Service Organizations)

399 Church St, 4th Floor, Toronto, Ontario, CANADA M5B 2J6.

Tel: 1 416 340-2437

**web-site : [www.icaso.org](http://www.icaso.org)**

(For regional offices, please refer to the "Resources" in the brochure "Basics to Get Started")

- **Canadian HIV/AIDS Legal Network**

417, rue Saint-Pierre, bureau 408 Montreal QC 2Y2M4 Canada

Tel : 514 397 6828 Fax : 514 397 8570

**e-mail : [enoler@aidslaw.ca](mailto:enoler@aidslaw.ca)**

**web-site : [www.aidslaw.ca](http://www.aidslaw.ca)**

- **Human Rights Internet, Canada**

8 York Street, Suite 302, Ottawa, Ontario, K1N 5S6

Tel: 1-613 789-7407, Fax: 1-613 789-7414

**e-mail: [hri@hri.ca](mailto:hri@hri.ca)**

**web-site : [www.hri.ca](http://www.hri.ca)**

- **Lawyers Committee for Human Rights**

333 Seventh Avenue, 13th Floor New York, NY 1001 Tel : 212 845 5200

Fax : 212 845 5299

**e-mail : [lchrbin@lchr.org](mailto:lchrbin@lchr.org)**

**web-site : [www.lchr.org](http://www.lchr.org)**

- **LawAsia**

LAWASIA Secretariat 11th Floor, NT House 22 Mitchell Street DARWIN, Northern Territory Australia 0800

Correspondence to : GPO Box 3275 DARWIN, Northern Territory Australia 0801

Tel : 61 8 8946 9500 Fax : 61 8 8946 9505

**e-mail : [lawasia@lawasia.asn.au](mailto:lawasia@lawasia.asn.au)**

**web-site : [www.lawasia.asn.au](http://www.lawasia.asn.au)**

- **Amnesty International**

Amnesty International, International Secretariat, 1 Easton Street, London WC1X 8DJ, United Kingdom.

**e-mail : [amnestyis@amnesty.org](mailto:amnestyis@amnesty.org)**

For the Amnesty International Office in your country, please see the web-site at :

**[www.amnesty.org](http://www.amnesty.org)**

For the "Health Professional Network" of Amnesty International, please see : **<http://web.amnesty.org/rmp/hponline.nsf>** ■





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Joint United Nations Programme on HIV/AIDS

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> I. Improving  
the Quality of  
Life of People  
Living with  
HIV/AIDS



## CARE AND SUPPORT

> II. Working  
with Injecting  
Drug Users in  
the Context of  
HIV/AIDS



# Improving the quality of life of people living with HIV/AIDS

**P**eople living with HIV/AIDS can live vigorous, healthy and productive lives when they have access to information, treatment, care and support.

- **Information** includes knowing what your rights are in terms of employment, welfare, education, family life, etc., and having clear information about treatment and how to get treatment.
- **Support** means many things: acceptance, respect, affection and help from friends and family and from the community. It also means supportive laws to protect against discrimination and stigma.
- **Care** includes moral support, counselling and access to the necessary medical treatment, to a good diet, to clean water, to accommodation (cf. For more information on access to treatment refer to the special section on this issue in the “Advocacy” brochure).

Although key human rights such as the right to information, the right to life and the right to health create entitlement to care and support, most young people living with HIV/AIDS do not have the necessary access to these services. Even where laws protect the human rights of people living with HIV/AIDS, many young people are being left alone when family, friends and their community learn about their HIV-positive status. Others choose to isolate themselves from the outside community.

The realisation of human rights in the context of HIV/AIDS, in particular the rights of people living with HIV/AIDS is not only a matter of state action to develop laws and policies that protect against discrimination and stigma. Advocacy for public policies and legal action is very important, too. (cf. “Advocacy” brochure). However this is not sufficient to make human rights become a reality at the grass roots, when it comes to improving the daily life of people living with HIV/AIDS. Don’t forget that to make human rights a reality at the grass roots, family, friends and the community have a very important role to play.

Assuming the responsibility to provide **information, care and support to their peers living with HIV/AIDS** is a task in which youth groups can make a very big difference. Offering their friendship, providing young people living with HIV/AIDS access to information on how to take care of themselves, setting up home visiting programmes for those who are sick, and organizing support services, are some of the possible actions to be undertaken.

If your group thinks about offering support in this way, the most direct and efficient way to begin would be to consult a group/organization that is already providing services to people living with HIV/AIDS. Almost certainly, they will have ideas about how your group can help. Below, we provide some examples of the kinds of activities in which youth groups show that they can make the difference...

## **TAKING GOOD CARE OF YOUR FRIENDS**

A good place to start showing your care and solidarity may be within your group, your family, with acquaintances or colleagues.

When someone you know has HIV/AIDS, you may feel helpless. You may be afraid of intruding on your friend’s privacy or simply not know what to say or do. Here are some tips on how you can help.

If you know that someone in your group has HIV or AIDS, it is important to make sure that friends who are already aware of his or her condition know that it is safe to touch, hug, share food and be together socially. At the same time, confidentiality should be respected. It is important to show that your regard for this person has not changed, and that you can continue to share friendship or joint activities in the same way as before.

If the person is sick, he or she will certainly need other forms of support, such as help with cooking, shopping, taking medicines, going out, cleaning or simply talking about his or her feelings.

HIV/AIDS related discrimination and stigmatisation also often occurs at the workplace. If you know a colleague who has HIV or AID, you may be able to help by making him or her as well as other colleagues aware of the rights of people living with HIV/AIDS at work. One concrete way to address such discrimination and stigma at the workplace is to advocate for behaviours and conducts which are consistent with international human rights standards. Here the “ILO Code of Practice on HIV/AIDS and the world of work” (available from [www.ilo.org](http://www.ilo.org)) may be a very useful tool.



“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 8, International Guidelines on HIV/AIDS & Human Rights.

### GROUP ACTIVITY

The following simple exercise helps to identify ways in which you can help somebody you know who has HIV/AIDS. A good starting point is to listen to personal stories by people living with HIV/AIDS.

Then, list all the ways they mention that you can help. Add any others that you can think of and discuss it together.

- Say hello
- Invite him or her for dinner

- Just listen
- Hold his/her hand
- Talk about the future
- Celebrate special days
- Ask how you could help
- Pick up medicines
- Give a hug
- Clean the house
- Share emotions, laugh, cry
- Others...

Source: School Health Education to Prevent AIDS and STD. UNAIDS/WHO/UNESCO, 1999

## "Teen Spirit" – a successful care and support programme for teenagers with HIV/AIDS

Teen Spirit is an organization that provides support to adolescents who are HIV-positive, or whose parents or other close relatives are living with HIV/AIDS. The group meets weekly and there are additional activities including one-to-one support, courses, a Newsletter team, a Music Project, and fun activities such as holidays together. Here are some comments made by young people who are involved in the group:

*"It's just nice to be with people around you who are going to listen"*

*"It's a place to unwind, listen to funky music - basically do what you want to do. You know that friends at Teen Spirit are always going to be there"*  
*"Without Teen Spirit I'd be locked up. I'd be quiet. I would not share my feelings with anyone"*

Teen Spirit is part of the organization "Body and Soul", which aims to provide a safe, confidential and supportive environment for people affected by HIV/AIDS. It promotes a holistic approach encompassing both peer and professional support to enable people to face the challenge of HIV/AIDS.

[See "Resources" below for contact details]



## THE MAGIC OF INFORMATION

Some people call information "the cheapest form of therapy": to develop youth-friendly HIV/AIDS information/resource services focused on the needs of people living with HIV/AIDS is not too difficult. A simple information leaflet, and discussions in peer groups, for example, can make a lot of difference.

**What information is important?** - People living with HIV/AIDS and those living or caring for them need up-to-date information on a range of issues. For example, carers need information to help them understand the progression of HIV and to know what advice to give; people with HIV need information to encourage them to seek early treatment for common illnesses, such as tuberculosis. They all need information about the rights of people living with HIV/AIDS, about options for treatment and how to get them.

*"To be informed is empowering. It has enabled me to manage living with the virus. I know how to take care of myself. I know my body, I understand it. I know where to seek support if I need it. I know what kind of support I need. I feel courageous about asking questions. Even to protest. I know what the choices are for me. And I am capable of making careful considerations before making any decisions. All this wouldn't have happened, or might have taken an awfully long time to happen, if I weren't informed".*

Suzana Murni, Echidna, Uganda, quoted in *AIDS Action*, Issue 43, 1999, Health link, London, UK.

## COUNSELLING

Counselling can be extremely helpful to anyone in a difficult or stressful life situation. This includes anyone going for an HIV test, anyone diagnosed HIV-positive, and caregivers looking after someone who is sick.

Training in counselling skills is very useful for anyone who provides care and support - from doctors and nurses to volunteers working on AIDS telephone help-lines or home visiting programmes.

If your youth group is preparing to work with people who have HIV or AIDS, counselling training could be a good start.

### Why counselling is important...

In India, YRG CARE (Centre for AIDS Research and Education) runs an integrated care programme that includes voluntary counselling and testing and hospital and home-based care services. They tell this story about one of their clients, which illustrates the importance and value of their counselling service: "Sangeeta had just given birth to a son. She was

delighted. But when her husband came to see her, the doctor told her that she had tested positive for HIV. She had received no counselling. She did not know about HIV and had not been told that she had been tested for it. After her diagnosis, her husband would not let her touch their son, and the medical staff left her alone".



### KEY PRACTICAL TIPS FOR CARE GIVERS

- Treat people living with HIV/AIDS with dignity and respect.
- Ask to visit or to go out together; do not stay away.
- Let them know that it is fine to talk about their feelings, or to show anger.
- Listen.
- If the person is sick, offer to shop/cook/clean; don't wait to be asked.
- Don't allow them to become isolated. Tell them about any support groups or other services that may be available in your community.

## RESOURCES:

Please refer to the "Resources" in the brochure "Basics to Get Started" for useful web-sites concerning HIV/AIDS issues in general.

1 • "ILO Code of Practice on HIV/AIDS and the world of work" available from [www.ilo.org](http://www.ilo.org)

2 • "Teen Spirit", a support group for teenagers living with HIV/AIDS. Teen Spirit is happy to exchange experiences and information with other youth organizations.

It can be contacted at: **Teen Spirit The Royal Homeopathic Hospital,**

60 Great Ormond St, London WC1N 3HR, Fax: + 44 20 7833 48989, e-mail: [paula@bodyandsoul.demon.co.uk](mailto:paula@bodyandsoul.demon.co.uk) ■



# Working with injecting drug users in the context of HIV/AIDS

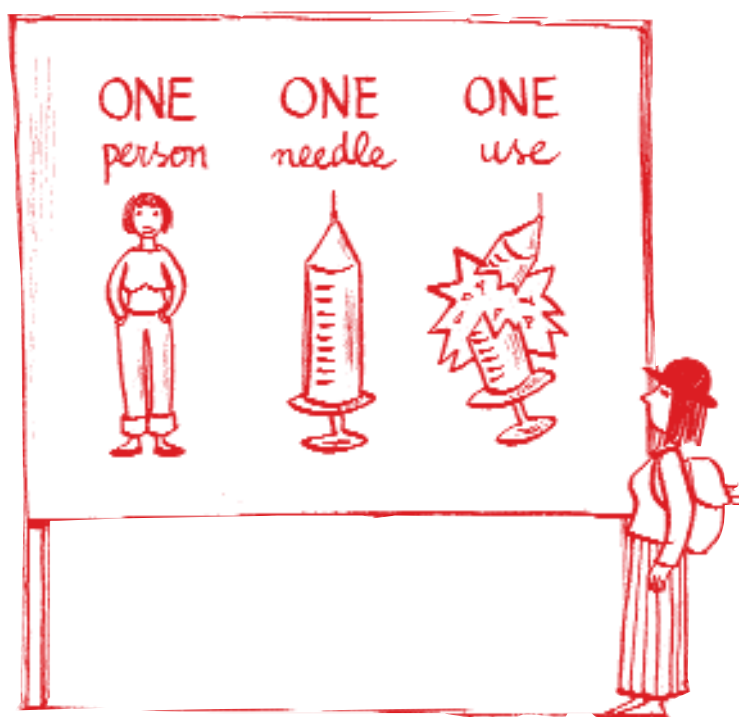
The use of injecting drugs has spread rapidly and it is now a reality in many countries. In some regions, such as Central and Eastern Europe, the sharing of syringes by drug users is one of the main sources of HIV infection. Drug users who are living with HIV/AIDS face a double stigma and exclusion from society.

Where programmes have been set up to help drug users, their purpose has been almost exclusively to get users to stop. These programmes remain crucial, but governments increasingly are recognising that this is not enough. New avenues for action have been developed, in particular “**harm reduction**”, including the prevention of HIV transmission.

“Harm Reduction” programmes aim to reduce health risks to injecting drug users and the community, for example by providing clean syringes and information about HIV/AIDS. These programmes have been endorsed and are encouraged by the United Nations.

**The International Guidelines on HIV/AIDS and Human Rights** specifically recommend that governments consider supporting needle and syringe exchange services and programmes to promote the best attainable health and welfare of injecting drug users.

The results of studies of harm reduction programmes in a range of countries, including the USA, Australia and Belarus, clearly show that they can significantly reduce new HIV infections among drug users. In Belarus, for example, a programme including education and the distribution of syringes and condoms, was estimated to have prevented over 2000 cases of HIV infection in only two years. The cost was US\$29 per infection prevented – far below the cost of an AIDS case to a family or a health system. (Source: *Report on the Global HIV/AIDS Epidemic*, UNAIDS, 2000.)



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 8, International Guidelines on HIV/AIDS and Human Rights.





## INTERVIEW

### Interview with a youth worker on Harm Reduction in Argentina

In Argentina, some non-governmental organizations have been trying to reach out to injecting drug users with help and information. Around 40% of AIDS cases are believed to be related to injecting drug use. However, needle exchange programmes were regarded as unacceptable until recently. In August 2000, the government announced that it would follow United Nations recommendations and support a policy of harm reduction for cases of injecting drug users who were at high risk of infection and were not attending withdrawal programmes.

*Intercambios*, a non-governmental organization, has been working with drug users in the city of Buenos Aires. They provide confidential advice, distribute free condoms and syringes and help people access the mainstream health services. Pablo Cymerman, is one of its youth workers:

**Question - How did you manage to reach drug users in your community?**

Many injecting drug users face criminalisation, discrimination and stigmatisation. They also find that the responses to their needs are very limited. Therefore, they stay away from the health services and other institutions. It is important to reach out to them, by listening to their needs and providing better responses. It is also essential to go to the places where they meet, rather than wait for them to approach an institution. In our case, we started by developing a relationship of trust with one drug user, who in turn introduced us to friends and acquaintances with whom we established relationships in their own contexts.

**Q - Were they suspicious that you might get them in trouble with the authorities?**

At the beginning they did not trust us. One drug user asked me, in our first encounter, whether I had connections with police. We managed to overcome this initial lack of trust by involving the drug user population in the activities, protecting confidentiality and anonymity, and sustaining our work over time.

**Q - Isn't it true that "harm reduction" methods encourage people to**

**continue using drugs?**

There are numerous international studies that show that harm reduction programmes, far from encouraging consumption, contribute to improving the quality of life of drug users and, in many cases, provide a stepping stone towards other health services.

**Q - What kind of advice can be given to injecting drug users?**

The main message to drug users is that they can look after their health and reduce the harm associated with drug consumption. We highlight the importance of not sharing any part of the equipment (needles, syringes, filters, water, etc), demonstrate safer injecting methods, teach how to prevent and respond to overdosing, and other ways of reducing risk. It is also important to raise awareness about the correct use of condoms during sexual intercourse.

**Q - What has been the result of the programme so far?**

We have been able to sensitise the community and to get better recognition from the official institutions for this type of work, which is demonstrably realistic and useful. Gradually, the response from the health services has improved. Drug users have taken part in the programme in increasing numbers and have themselves started spreading the message of prevention.

**Q - What role do pharmacies play in your programme?**

Injecting drug users are certain to visit pharmacies. Therefore, these are important allies in prevention programmes. Pharmacies can disseminate information and provide access to sterilised injecting equipment and to condoms. They can also advise about health and social services available in the community.

**Q - What advice or suggestions would you give to youth groups who want to start harm reduction programmes in their communities?**

The first step is to get rid of the notion that abstinence is the only worthwhile aim, and to adopt realistic and pragmatic objectives. Another important point is to involve drug users in the activities and to listen carefully to their needs and suggestions.



## GROUP ACTIVITY

### Challenging stereotypes

**People who work with drug users in the context of HIV have to confront stereotypes at two levels - their own and those of workers in other agencies with whom they need to liaise. This activity helps people to look at what the stereotypes might be and to develop strategies for challenging them.**

#### AIMS

- To confront one's own stereotypes about drug users
- To think about how stereotypes and attitudes can be changed
- To develop skills challenging people who express negative and stereotyped views of drug users.

#### DESCRIPTION

- Prepare a set of statements representing stereotypes about drug users in your community. For example: "Drug users are people with serious social and

*emotional problems*". "There is no difference between drug users with AIDS and smokers dying of lung cancer". "Drug users are uneducated and stupid". "Drug users can't be trusted. They exploit everyone who tries to help them". "Drug users are all criminals and should be dealt with by the police and prison service alone".

- Work in small groups. For each statement, each person in the group should say how strongly they agree or disagree. Next, each group should discuss differences of opinion.
- Call back all the groups and ask each one to report back on the statement that caused the most disagreement. Discuss the comments that people made.
- Ask if anyone wants to comment on any of the other statements.
- Draw the activity to a close by asking people for other comments they've heard about drug users, and how they would counter them.

**Points to highlight: What ways have people found to challenge stereotypes?**

**Source:** "Living on the Edge - Coping with HIV/AIDS and Drug Misuse", Training Guide, 1993 by The Community and Education Development Centre.





## KEY PRACTICAL TIPS FOR PROGRAMMES ON DRUG USERS

- Build trust on the basis of respect and confidentiality.
- Involve users in the programme and listen carefully to their needs and suggestions.
- Combat stereotypes.
- Remember that stopping consumption is not the only worthwhile objective.
- Reach out into the drug-user population, do not wait for them to approach an institution.
- Involve drug users in evaluating your activity.

## RESOURCES:

Please refer to the “Resources” in the brochure “Basics to Get Started” for useful web-sites concerning HIV/AIDS issues in general.

- 1 • Information and support networks created to link and support the people and programmes working to stop HIV among injecting drug users:

- **The Asian Harm Reduction Network**

PO Box 235, Prasingha Post Office Chiangmai, Thailand 50200

Tel: 66 53 89 41 12 fax: 66 53 89 41 13

e-mail : [ahrn@loxinfo.co.th](mailto:ahrn@loxinfo.co.th)

web site : [www.ahrn.net](http://www.ahrn.net)

- **The Canadian Harm Reduction Network**

e-mail : [noharm@canadianharmreduction.com](mailto:noharm@canadianharmreduction.com)

- **Central Eastern European Harm Reduction Network (CEE-HRN) :**

P.O. 2357 Szeged, Hungary 6701

e-mail : [emilissubata@takas.lt](mailto:emilissubata@takas.lt)

- **Harm Reduction Coalition and Harm Reduction Training Institute**

22 West 27th Street, 5th Floor New York N.Y, 10001

Tel: 212 213 63 76 Fax : 212 213 65 82

e-mail : [hrc@harmreduction.org](mailto:hrc@harmreduction.org)

web site : [www.harmreduction.org](http://www.harmreduction.org)

- **Latin American Harm Reduction Network**

Relard Secretaria, Av. Campos Sales 59, Vila Mathias, Santos, SP, Brazil, CEP 11013-401

Tel: 55 13 235 48 52

e-mail : [relard@data54.com](mailto:relard@data54.com)

- 2 • UNAIDS Documents at [web-site : www.unaids.org/bestpractice/digest/index.html](http://www.unaids.org/bestpractice/digest/index.html)

under the topic “Injecting Drug Users”, for example: “SHAKTI: Working with injecting drug users in Bangladesh”, Aug. 2000.

- 3 • UNAIDS Project : “HIV/AIDS Prevention among IDUs –Ukraine”, further information can be obtained from:

- UNAIDS Best practice cases at:

[www.unaids.org/bestpractice/summary/idu/previdu.html](http://www.unaids.org/bestpractice/summary/idu/previdu.html)

- or from the implementer, a locally based NGO :

**Public Movement “Vera, Nadesha, Ljubov”**

sq. Molodi, 17 Odessa, Ukraine

Tel: 380 482 234 767 Fax: 380 482 268 248

- 4 • UNDCP has a global youth Network at :

[www.undcp.org/global\\_youth\\_network.html](http://www.undcp.org/global_youth_network.html) ■

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 8, International Guidelines on HIV/AIDS and Human Rights.



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E-mail : [unaids@unaids.org](mailto:unaids@unaids.org) • Internet : <http://www.unaids.org>



## GLOSSARY



# Human rights terms and institutions

**Commission on Human Rights** : Body formed by the Economic and Social Council of the UN to deal with questions of Human Rights. (Also see UN Human Rights Bodies)

**Committee on Human Rights** : Created under article 28 of Covenant on Civil and Political Rights to promote and encourage the development of human rights and fundamental freedom. (Also see UN Human Rights Bodies)

**Council of Europe** : Regional organization comprised of 34 European countries that subscribe to the rule of law and human rights, submitting to the binding jurisdiction of the European Court of Human Rights (ECHR). (Also see European Convention on Human Rights)

**Criminal Law** : A phrase that often includes the entirety of what we know as the administration of criminal justice, can encompass several legal fields: substantive criminal law, criminal procedure, law enforcement, and penology.

**European Convention on Human Rights** : The Convention for the Protection of Human Rights and Fundamental Freedoms, normally referred to more simply as the European Convention on Human Rights was drafted by the Council of Europe and adopted in 1950. Acceptance of the convention, of the jurisdiction of the European Court of Human Rights in interpreting it, and of the right of individuals to petition the **European Court of Human Rights** for protection are now obligations of membership in the Council. Almost all Member States have incorporated the convention into their domestic law, so their own courts can apply it where an individual claims a breach of one of the rights it contains. A citizen can petition the European Court of Human Rights itself only after all remedies available in his/her home country have failed to satisfy him/her. In a state where the convention has not been incorporated he/she may not be able to get final judgement of the case against his/her government until years after the act.

**Human Rights** : Human rights are the rights and freedoms of all human beings. They are fundamental and universal. Human rights consist of civil and political rights as well as economic, social and cultural rights.

**Inter-American Court of Human Rights** : Court established in accordance with the American Convention on Human Rights. It is an autonomous judicial institution whose purpose is the application and interpretation of the convention. Only the state parties and the Inter-American Commission on Human Rights have the right to submit a case to the court.

**International law** : The system of law regulating the interrelationship of sovereign states and their rights and duties vis-à-vis one another. International law also covers private international law, or the conflict of laws. In this broader sense, international law is concerned with the rights of persons within the territory and dominion of one nation, by reason of acts private or public, done within the dominion of another nation.

**NGO** : Non-governmental organization.

**Repeal of Law** : A legislative act abrogating an earlier act.

**Right** : An interest or expectation guaranteed by law.

**State Party** : A state that has signed and ratified a human rights treaty. State parties are committed to incorporate the rights in the treaty into their own national and municipal law. They are also obliged to comply with all provisions of the human rights treaty.

**Treaty, convention, pact, act, declaration, protocol** : Contracts between states are called by these various names, none of which has a single fixed meaning. A treaty is the most formal type of agreement as it is not just a declaration of intent, it creates obligations on Member States and it is governed by international law.

**Treaty law** : An international term for law on international agreements between states, between states and international organizations or between two or more international organizations. The two prime United Nations (UN) Human Rights Treaties are the International Covenant on Civil and Political Rights (ICCPR) and Covenant on Economic and Social Rights (ESCR). Other universal treaties (including charters, conventions, covenants and statutes), regional treaties and protocols to treaties comprise the principal body of International Human Rights treaty law. The 1969 Vienna Convention on the law of treaties is the central source of international law on treaties.

**Universal Declaration of Human Rights** : In 1948, the General Assembly of the United Nations adopted the Universal Declaration of Human Rights "as a common standard of achievement for all peoples and nations". Although the Universal Declaration of Human Rights is not legally binding, over the years its main principles have acquired the status of standards which should be respected by all states.

**UN** : United Nations. The United Nations is an international organization, central to global efforts to solve problems that challenge humanity. More than 30 affiliated organizations, co-operating together constitute the UN system. UN and its family of organizations work to promote respect for human rights, protect the environment, fight disease, foster development and reduce poverty. UN agencies define the standards for safe and efficient transport by air and sea, help improve telecommunications and enhance consumer protection, work to ensure respect for intellectual property rights and co-ordinate allocation of radio frequencies. The United Nations leads the international campaigns against drug trafficking and terrorism. Throughout the world, the UN and its agencies assist refugees and set up programmes to clear landmines, help improve the quality of drinking water and expand food production, make loans to developing countries and help stabilise financial markets.



**UN Human Rights Bodies** : The United Nations human rights bodies are of two types; those which derive their existence from relevant provisions of the UN Charter and those which derive their existence from UN Human Rights treaties.

THE CHARTER BASED BODIES ARE : the **Commission on Human Rights and its Sub-commission on Prevention of Discrimination and Protection of Minorities**. They are the main UN bodies with a general and broad mandate to cover all areas of human rights. There is also the **Commission on the Status of Women** which focuses on issues related to the human rights of women.

KEY TREATY-BASED BODIES DIRECTLY RELEVANT TO HIV/AIDS ARE: the **Human Rights Committee** established by the provisions of the International Covenant on Civil and Political Rights; the **Committee on Economic, Social and Cultural Rights**, established by the provisions of the International Covenant on Economic, Social and Cultural Rights; the **Committee on the Elimination of Discrimination against Women**, established by the provisions of the Convention for the Elimination of All Forms of Discrimination against Women; and the **Committee on the Rights of Child**, established by the Convention on the Rights of the Child.

**UN International Covenant on Civil and Political Rights** : This covenant elaborates the political and civil rights identified in the Universal Declaration of Human Rights, which include mainly : the rights to life, privacy, fair trial, freedom of expression, freedom of religion, freedom from torture and equality before the law. (Also see UN Human Rights Bodies)

**UN International Covenant on Economic, Social and Cultural Rights** : The rights recognised by the covenant include mainly : the rights to work, form and join trade unions, social security, protection of the family, the highest attainable standard of physical and mental health, education and participation in cultural life.(Also see UN Human Rights Bodies)

# Medical terms

**AIDS** : “Acquired Immuno-Deficiency Syndrome”, a serious disease caused by the HIV virus which destroys the immune defences of the body, which is then subject to serious “opportunistic” infections and certain cancers.

**Anti-retroviral drugs** : Substances that reduce the viral load and strengthen the immune system; all are proprietary and therefore expensive, and must be used in combination in order to be effective.

**Combination therapy** : The use of more than one drug to treat a disease

**Compulsory licensing** : Authorisation to a government or company to make and sell a drug without the permission of the patent holder, allowed only in public health emergencies.

**Generic drugs** : Drugs without a brand name, which can be manufactured without a licence, usually after the patent held by the original owner has expired.

**HIV** : Human immuno-deficiency virus, which causes AIDS. There are two main types of the virus : HIV-1, which is responsible for the world wide pandemic of AIDS, and HIV-2, which can also cause AIDS and occurs mainly in West Africa.

**Kaposi's sarcoma** : A form of cancer involving multiple tumours of the lymph nodes or skin, occurring especially in people with depressed immune systems. e.g.; as a result of AIDS.

**Lymphoma** : Any malignant tumour of the lymph (colourless fluid containing white blood cells, drained from the tissues and conveyed through the body in the lymphatic system) nodes.

**Opportunistic infection** : An infection induced by a micro-organism that is usually well tolerated by the body and only becomes pathogenic when the body's defences are depressed. The most serious manifestations of AIDS are caused by opportunistic infections.

**Palliative care** : Relief of suffering

**Parallel importing** : When a country without the ability to manufacture a drug, buys it from another country where it may be cheaper than the price demanded by the patent holder.

**Patent** : Legal ownership of an invention or discovery, usually granted for 20 years.

**Proprietary drugs** : Drugs “owned” by a pharmaceutical company; exclusively made and sold under a brand name by the patent holder or a licensee.

**Resistance** : When a virus develops the ability to “resist” a drug; which normally happens when treatment is interrupted or doses are frequently missed, or taken in unsuitable combinations; resistance can spread together with the virus.

**Seropositive or HIV-positive (HIV+)** : Refers to a person with a positive screening test for antibodies to HIV. This person has been in contact with HIV and should be considered to be potentially contagious by his/her blood and by sexual relations. When the test does not detect antibodies, the person is said to be “seronegative” or “HIV-negative”.

**STD** : Sexually Transmitted Diseases, i.e. diseases that can be contracted by means of sexual relations. AIDS is essentially a sexually transmitted disease.

**Viral load** : The amount of virus in the blood

**Virus** : An infectious agent. Viruses are responsible for numerous diseases in all living beings. They are extremely small particles (which can only be seen under the electron microscope) and, unlike bacteria, **can only survive and multiply within a living cell** at the expense of this cell. (eg: HIV: human immuno-deficiency virus, which causes AIDS)

See also UNAIDS Glossary page at : [www.unaids.org/publications/glossary.asp](http://www.unaids.org/publications/glossary.asp) for “Glossary of AIDS-related terminology”. ■

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Joint United Nations Programme on HIV/AIDS

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## UNESCO

United Nations Educational, Scientific and Cultural Organization (UNESCO) is mandated to contribute to peace and security in the world by promoting collaboration among nations through education, science, culture and communication in order to further universal respect for justice, for the rule of law and for the human rights and fundamental freedoms.

UNESCO's contribution to the fight against the HIV/AIDS pandemics, in co-operation with UNAIDS co-sponsors, Member States, civil society partners and the private sector, concentrates on :

- Integrating HIV/AIDS preventive education into the global development agenda and national policies,
- Adapting preventive education to the diversity of needs and contexts,
- Encouraging responsible behaviour and reducing vulnerability,
- Exploring the ethical dimensions of the HIV/AIDS pandemic.

## UNAIDS

The Joint United Nations Programme on HIV/AIDS (UNAIDS) is the leading advocate for global action on HIV/AIDS. It brings together eight UN agencies in a common effort to fight the epidemic: the United Nations Children's Fund (UNICEF), the United Nations Development Programme (UNDP), the United Nations Population Fund (UNFPA), the United Nations International Drug Control Programme (UNDCP), the International Labour Organization (ILO), the United Nations Educational, Scientific and Cultural Organization (UNESCO), the World Health Organization (WHO) and the World Bank.

UNAIDS both mobilizes the responses to the epidemic of its eight cosponsoring organizations and supplements these efforts with special initiatives. Its purpose is to lead and assist an expansion of the international response to HIV on all fronts: medical, public health, social, economic, cultural, political and human rights. UNAIDS works with a broad range of partners – governmental and NGO, business, scientific and lay – to share knowledge, skills and best practice across boundaries.



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