Increasingly AIDS organisations and activists acknowledge that two very significant barriers to successful HIV prevention are discrimination and inequality. Fear and ignorance about AIDS have led to discrimination against people living with HIV and those assumed to be 'high risk' because of their lifestyle or sexual partners.

While HIV can affect anyone, people—especially women—who lack access to information or health services, and who have little choice about what they do sexually, are most vulnerable to HIV. If they test HIV positive or become sick, they are even more at risk of discrimination. Discrimination can mean being dismissed from work, refused health treatment and avoided or attacked.

One response to the epidemic has been to introduce measures which restrict the freedom of infected or vulnerable people. These traditional public health measures were used to control epidemics such as tuberculosis or syphilis. They were based on compulsory testing, isolation of those with the illness and treatment to prevent others from becoming infected. However, it has become clear that these measures have far too high a social and financial cost.

Policies of isolation and compulsory testing make it easier to blame certain groups of people. Therefore most people do not feel at risk and so do not take steps to prevent HIV. At the same time people need information but may be afraid to seek advice and support.

Many AIDS organisations and health services are now working in close partnership with people with HIV to respond to the epidemic more successfully.

Dr Juan Carlos de la Concepción, on page 5, describes how he and other HIV-positive people in Cuba worked with their government to change the policy of compulsory isolation. They did this because they felt that this policy was preventing the wider public from coming to terms with the realities of HIV and the need for safer sex.

'We don't fear the virus or even death so much as the way in which others treat us.' On page 4, activists from Uganda emphasise the importance of being open about HIV. This not only helps others personalise the risk, but also makes it easier for them to negotiate protected sex.

But individuals who feel safe enough to be open about their HIV status are in a tiny minority. In most countries, people still risk losing everything—home, job, children, friends and family. Continuing to work against discrimination and for people's human rights is a vital part of the fight against HIV.
Some NGOs and individuals are using human rights approaches to challenge HIV-related discrimination. Respecting human rights means that all people are treated as equal in human worth and dignity, whoever they are. A Universal Declaration of Human Rights was agreed in 1948 and has since been signed by almost all nations. There are more recent international agreements on rights which are legally binding for nations who have signed them.

Of course, human rights are not only relevant to HIV—many people do not have access to minimum basic needs. But there are some forms of discrimination that directly affect people living with HIV or make some groups of people more vulnerable to infection.

APCASO members (Asia Pacific Network of AIDS Service Organisations) are developing a set of guidelines based on internationally recognised human rights and applying them to HIV. This is helping the NGOs to define and document HIV-related discrimination (see page 3). This makes it easier to campaign for policies and programmes that respect human rights, as well as provide better care and enable people to reduce their risk of HIV infection.

For more information about APCASO Human Rights Initiative contact APCASO, Kabalikat Ng Pamilyang Pilipino, 3rd Floor B & M Bldg, 116 Aguirre St, Legaspi Village, 1229 Makati, Metro Manila, The Philippines.

**Small actions, big changes**

“Advocacy” means carrying out activities which achieve wider public understanding about issues, and changes in policies, laws and health or education services. It may involve political demonstrations but more often is a gradual process of informing and persuading key people that policy change or providing more resources is the best way forward. Advocacy involves voicing the interests and concerns of affected groups. This means including them in planning and listening to their needs.

Small organisations may fear that advocating policy change is too difficult, or that they lack skills and will be unable to change attitudes or services. It is true that national level lobbying is needed to achieve major policy changes, as happened in Cuba (see page 7). But very effective local campaigns often focus on broadening public acceptance and taking on specific issues, such as the examples on page 3.

Before starting, think about these issues:

- Why do you want to challenge the existing situation and what do you hope to achieve?
- What precise issues will you focus on, and what changes do you want? Choose a few key messages, and explain clearly how you propose to make these changes and show that they are possible.
- With whom do you want to work during the campaign? Who needs to be involved and who will strengthen your message (alliances between groups for people with HIV, health workers, human rights groups, lawyers, celebrities, religious leaders, politicians, unions, NGOs)?
- Whom do you need to influence (media, policy makers, local NGOs or the hospital, church or mosque)?
- What information will best explain your arguments and back up your demands? Make sure you have all the facts about the situation and that your arguments are persuasive and appeal to people’s self-interest.
- How and when will you get your message across (letters, meetings, rallies, press releases, interviews, information updates and fact sheets)?

and human rights

Practical activities

Creating awareness of HIV and reducing stigma The Philly Lutaaya Initiative is one example of a group of people with HIV who provide public education and aim to encourage attitude change and a more supportive environment (see page 4).

Educating health workers Women Fighting AIDS in Kenya (WOFAK) is a self-help group of women living with HIV. An HIV-positive woman asked WOFAK for support in getting a health worker to assist at the delivery of her baby. This had been refused because she was HIV positive. WOFAK met local health workers and one doctor agreed to assist at the birth. WOFAK now plans to work with other health workers to reduce their fears about infection.

Developing a workplace AIDS policy In Zimbabwe, trade unions, employers and NGOs have jointly agreed a policy which prevents employers from testing employees for HIV. In South Africa the same process has led to a parliamentary bill on HIV employment policy. The AIDS and Law Network works with employers and unions to lobby and change policy. It provides public education using pamphlets on HIV-related rights and training for community legal advisors.

Improving women’s status FIDA Kenya, a women lawyers organisation, provides domestic violence awareness training to police officers. Many women dare not refuse unprotected sex with their husbands for fear of violence. The training links domestic violence and HIV infection and has changed some police officers’ attitudes. They are encouraging colleagues to take domestic violence seriously and have designed posters for display in local police stations.

Ensuring housing rights In India one NGO works with local housing associations to integrate HIV awareness into their campaigns on housing, to prevent HIV-positive people from being evicted.

Supporting prisoners rights The AIDS and Law Project in South Africa provides HIV awareness training to prison officers and prisoners, and legal representation for prisoners with HIV.

Internationally accepted human rights

These principles are from the Universal Declaration of Human Rights. The abuses listed are possible examples – these vary depending on national laws and policies and local circumstances.

Liberty, security and freedom of movement
- compulsory HIV testing
- quarantine, isolation and segregation

Freedom from inhumane or degrading treatment
- isolation, for example of HIV-positive prisoners
- participation in research trials without informed consent

Equal protection of the law
- denying access to legal advice or services

Privacy
- lack of confidentiality or disclosure of test results without consent
- compulsory reporting of people with HIV to health authorities (making HIV a notifiable disease)

Right to marry or have relationships and children
- forced abortion or sterilisation
- compulsory pre-marital HIV testing
- discrimination against same sex relationships

Self-determination
- banning groups organised by people vulnerable to or affected by HIV

Equal access to health care
- lack of appropriate drugs or condoms
- refusal to care for or treat people with HIV

Education
- lack of access to information which enables people to make informed choices
- refusal to provide education because of HIV status

Shelter, social security and housing
- denial of access to housing or social services

Work and security
- dismissal from, or discrimination at, work
- limited or no insurance cover or other benefits
- HIV testing as a pre-condition of employment

HIV tests are no longer done without consent and prisoners with HIV are not segregated. Prisoners say officers are much more aware of HIV-related issues. With thanks to Renée Danziger (UK) and Dorothy Odhiambo (Kenya).
**Being open, educating others**

In Uganda people living with HIV are organising themselves and publicly speaking out.

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**Major Ruranga**

*Major Ruranga is living with HIV and is an officer in the Ugandan Army.*

‘Uganda has faced up to the reality of AIDS. One reason for this is that our leaders have accepted the problem. For example, our President always stresses that we need to fight HIV/AIDS in order to fight poverty in Uganda.

But most people in Uganda still think that HIV only affects the poor or soldiers, drivers and prostitutes. Many wealthy and educated Ugandans are not open about AIDS. These people tend to go abroad for treatment and hide the fact that they have HIV.

It is very important for powerful people who have HIV to come out openly. Keeping quiet does not reduce the pain that HIV inflicts on us. I have become involved in HIV education because I feel that people listen to and believe the voices of those who are already infected and affected more than those who are not. Better prevention can be achieved if respected and important public figures do not hide away from the issue. Everybody must join the fight because there is no need to be ashamed of a disease that does not recognise borders and can affect anyone, whatever their position in society.

**Major Rubaramira Ruranga, Guidance and Empowerment Network, c/o Joint Clinical Research Centre, PO Box 10005, Kampala, Uganda.**

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**Reverend Gideon Byamugisha**

*Reverend Gideon Byamugisha is an HIV-positive Anglican priest.*

‘I hope, as a priest openly living with HIV, that other priests will feel able to be frank about HIV and that if people see that a priest can get HIV they will realise that everyone is vulnerable.

Religious institutions can be great assets in the fight against AIDS. Their members have daily contact with people and are dependent upon for reliable information. But without accurate information about HIV they can be a big hindrance to education, especially if they are reluctant to discuss sexuality for religious and cultural reasons.

Religious divisions over condoms are unhelpful. We should accept the ‘multi-frontline’ approach to HIV prevention and choose which line to fight on, without attacking those fighting on other fronts.

For three years I have been teaching church leaders about HIV prevention and care. At first they tend to say that people living with HIV should be separated and that AIDS is a curse from God. However, after an awareness raising session they change their views.

HIV is linked to community and family relationships, including marriage. Unequal relations between men and women put women at higher risk of infection. Life skills are not included in school education for young people while unequal relationships at work and exploitation and low wages make many people vulnerable.

**Reverend Gideon Byamugisha, PO Box 14297, Kampala, Uganda.**

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The Philly Lutaaya Initiative (PLI) is a group of men and women with HIV who educate others by sharing their personal stories.

‘This project started in 1991. Our aim is to give AIDS a human face by talking to groups in the community. This encourages others to think more personally about HIV, supports those who are trying to remain free of HIV and reduces the stigma for people with HIV/AIDS.

At public sessions audiences ask many questions, such as: How have you benefited from going public? How did you get the courage to take an HIV test? Have you told your children? We try and answer as honestly and openly as possible.

Each of us has a different story – some of us have children and others do not, some have chosen to abstain from sex and others have a healthy sexual life using condoms.

After our sessions many people decide to change their behaviour or seek further counselling and a test.

**Philly Lutaaya Initiative, PO Box 10446, Kampala, Uganda.**

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Below: PLi members talk to young people about living with HIV.
A positive response

Collaboration between people living with HIV, health workers and policy makers has changed policy in Cuba, Latin America.

From 1986 to 1990 Cuba’s national AIDS policy included compulsory isolation for people with HIV in special sanatoriums, which included family visits and, shortly afterwards, weekend passes. In 1989 a group of HIV workers and people living with HIV began questioning these policies, arguing that people living with HIV need to be able to mix freely with others in order to reduce fear of HIV.

In 1990 people living with HIV and resident in Cuba’s main care and prevention centre, the Sanatorium Santiago de las Vegas, formed the AIDS Prevention Group (GPSIDA). We aimed to make our voices heard, do AIDS education in the community and campaign for the right to be treated with respect.

After training ourselves as prevention educators we began working with the National AIDS Programme to ensure that their information was accurate and challenged the prejudices that people have about HIV. We targeted teacher training colleges and workplaces and used TV and radio to reach families and young people. In the ‘Learning to live with HIV’ project GPSIDA collaborated with staff at a test counselling centre, providing support and counselling to those who had just tested positive.

Partly as a result of GPSIDA’s work, in 1993 sanatorium residents were given the choice of continuing to stay in the sanatorium or returning home and receiving outpatient or home care provided by a network of family doctors based in the community. This was a decisive step towards integration of people with HIV into Cuban society.

GPSIDA educated and prepared people for the changes.

As well as changing our own country’s policies, GPSIDA members and others have struggled hard to challenge assumptions elsewhere that Cubans who test positive for HIV have only one destiny — sanatoriums. We have always appreciated the benefits that the Cuban health system provides — HIV-positive Cubans get treatment and care including up-to-date medication, balanced diets and psychological support. The right to life, free health care, treatment and education are the main priorities for Cuba. When Cuba’s AIDS policy is criticised our health system must be compared to those of other countries where there is less access to health care for all, including people living with HIV.

GPSIDA has always dreamt that our experience, though not perfect, can be a reality for people with HIV in other poor countries.

Dr Juan Carlos de la Concepción Raxach, founder member of GPSIDA, currently studying in Brazil.

GPSIDA, Sanatorio Santiago de las Vegas, 1½ km carretera al Rincon, Santiago de las Vegas, Ciudad de la Habana, Cuba.

Right to know

Access to health information is a human right. This applies to HIV information, including how the virus is transmitted sexually between men. In most societies men have sex with other men. Some men are afraid to be open about who they have sex with because of fear of violent attack or discrimination. Others do not consider themselves homosexual (gay) but sometimes have sex with other men even though they normally have sex with women — for example, men in prisons or single-sex hostels.

HIV projects need to include information for men who have sex with men. Lack of information leads to a higher risk of contracting HIV. For example, some prisoners believe that they are not at risk of getting HIV because they are only having sex with men, not with women. Some men have even said to me that they opt to have sex with men because they think it is safer than women.

Disbelief and discrimination make it difficult for people to raise these issues and to design appropriate programmes. AIDS organisations are themselves often unwilling to admit that sex between men happens. The public, politicians and the media need to be educated.

Groups and organisations of gay men and lesbians are being formed across Africa. In South Africa the Township AIDS Project has a Gay and Lesbian Programme where black gay men and lesbians learn about HIV and safe sex and share experiences. Similar groups have also been set up in Botswana, Kenya and Zimbabwe.

Recent threatening and discriminatory statements from a few political leaders in Africa and elsewhere make it difficult for gay groups and people working with men who have sex with men. As well as fighting discrimination against people living with HIV, community-based and human rights organisations need to challenge this discrimination and develop appropriate education and outreach programmes. It is important for everyone to be able to live without fear of being stigmatised because of what they do sexually, and to be able to discuss these issues.

Simon Nkoli (formerly of Township AIDS Project Gay and Lesbian Programme), Positive African Men Project, PO Box 23017, Joubert Park, 2044 Gauteng, South Africa.

On the margins: men who have sex with men and HIV/AIDS in developing countries describes the political and social contexts in which men have sex with men, and government and NGO responses.

Available free to NGOs and AIDS service organisations in developing countries from PANOS Institute, 9 White Lion Street, London N1 9PD, UK.
Self-help or support?

‘Support groups are the best medicine’ says an HIV-positive woman, but their success depends on having clear aims.

Many local groups have been set up by or for people living with HIV/AIDS. They are not easy to organise and do not always meet every HIV-positive person’s needs. However, they can be a great source of help and an advocacy tool, both locally and nationally.

Self-help groups can provide:
- emotional and social support at home or in group sessions
- opportunities to meet, and share ideas and practical information with others who face similar issues
- training in education, public speaking and counselling skills
- opportunities for getting loans or earning an income
- a basis for advocacy and campaigning.

It is important for the co-ordinator or founder members to be clear about the main purpose of the group and discuss this with new members. Women and men with HIV have very different needs and concerns — depending on how long they have known they are HIV positive, their state of health, their financial situation and family responsibilities.

Groups work best when their members have similar expectations. For example, recently diagnosed people may not wish to become involved in campaigning or education work. The Post Test Club of the AIDS Information Centre in Uganda offers peer counselling and practical information to people who have recently taken an HIV test. The Wednesday Club of the Thai Red Cross is run by people currently receiving treatment who want to share information.

It is easy to become discouraged if members leave but this does not always mean failure. Perhaps people join during a particular crisis, for example shortly after diagnosis. When the crisis passes they may prefer not to continue.

Some people may need material support, such as money or food, rather than the opportunity to talk. Make sure that people know if your group cannot provide this and consider whether you or another organisation can respond to these needs with a different project. One women’s group in Zimbabwe saw the need for economic support, and set up a successful tailoring business with a supportive working environment. It has decided that it cannot accept new members.

Meeting as a group may not always be appropriate. A group in Côte d’Ivoire found that few women join because they are afraid for their children if their HIV status becomes known. Members visit women individually at home.

Groups are more likely to succeed if they are run by people living with HIV and where members share similar experiences, for example as women or as injecting drug users.

Support and self-help groups can play an important role in advocacy. By enabling people living with HIV to get together it is easier to be open and become involved in prevention and care. This shows others that people with HIV are living positively, sharing the burden of policy and education work.

Thanks to Emily Chigidwe (Zimbabwe), Joanne Manchester (UK), Nina Okagbwe (Côte d’Ivoire) and Dorothy Odhiambo (Kenya).
Many income generating schemes end in disappointment. AIDS Action highlights issues to consider before starting.

The most serious problems faced by people living with or affected by HIV are poverty and inequality. Income generating activities aim to solve these problems but often fail. Many create extra work for members with little economic reward. Others may improve incomes in the short term but fail because they depend on continuing outside support.

The real barriers to improving income may not be economic at all, but social or cultural. For example, increasing women’s income may simply result in their partners taking the money. It is important to think about possible problems and barriers before beginning an income-generating project, and to consider other options for addressing poverty.

Credit schemes can improve financial security for small businesses.

Responding to needs
Is the activity intended to be a viable business enterprise or to provide social support to people? Income-generating projects can provide personal, as well as material, benefits, but this aim needs to be clear from the start so that people do not have unrealistic expectations.

Is the main aim to provide financial security to people who are in need? If so, find out what sources of support already exist locally, for example:

- referring people to church or welfare groups
- providing assistance to obtain government benefits
- creating welfare funds for small one-off payments
- establishing vegetable gardens or helping people to produce household articles for family use.

Before planning a new activity think about improving existing employment options, which might include:

- identifying local employment needs and planning appropriate training
- arranging temporary work with local employers
- training people who already run small businesses in production or business management.

Saving and borrowing
A common problem for people trying to start a business is lack of access to credit (loaning money on a commercial basis to be paid back, usually with interest).

Are there any local credit or savings schemes such as Islamic credit schemes, women’s savings groups or revolving loan funds? These schemes involve members making regular small contributions to a fund which entitles them to an occasional loan or payment.

Consider all the real costs of setting up a credit scheme, including salaries and office rent. A service charge may be needed to cover the running costs, especially in rural areas where communications are costly.

Plan the scheme carefully, making sure that people understand the need for repaying money with interest. Give adequate support to beneficiaries, such as ensuring women members have access to literacy and basic financial skills and child care.

Enterprise
If you think there is a business opening, first ask yourself why no-one is doing it already. Business enterprises fail for many reasons, including lack of training, skills or access to markets. Test your ideas with local, sympathetic entrepreneurs or business development projects.

If you do plan to set up an income generation project think about who will be involved. The best projects are often those set up by the potential participants themselves.

Should the project work with individuals or groups? Working in a group is not always easy. Different members may have different aims. However, costs can be reduced if a group pays for materials or transport. Make sure that individuals benefit directly from group membership.

Be clear about your organisation’s capacity to cope with the increased work load and ability to carry out a commercial enterprise.

Financial sustainability is not always possible, especially where there is high inflation, sickness or conflict. In these situations, external donor support may always be needed. It is important to remember the other benefits of income generating activities as well as, or instead of, improving financial security. If a project is well-targeted and efficient, clients gain not only income (their dependents also benefit indirectly) but also new skills which may contribute towards increasing control over their lives.

Thanks to Judy el-Bushra, ACORD, UK.

AIDS support and income generation, 1994, Global AIDS News 4, Jackson, H, Mouli, V C & Udwin, M.
Fighting injustice

I am 41 years old and several years ago chose to volunteer as a home carer with my local church. I already knew about the experiences of people living with HIV, having seen two of my relatives go through physical suffering and mental pain caused by others avoiding people with AIDS. I received training in pastoral counselling and pre- and post-test counselling. Shortly after volunteering I decided to take an HIV test myself. My husband’s first wife was quite sick and I wanted to know for myself. I was influenced by the example of the many people with HIV dying with dignity.

When I received the news that I was positive I was emotionally out of it for some time. I didn’t know what I was hearing, I was worried about my daughter. I asked the counsellor to pray with me and then returned to my HIV training class.

I have chosen to tell other people because I want to be honest with them. I first shared my news with the nursing sister, my pastor, and then with the eighteen other counsellors. I did so because I wanted to talk to people about the dangers of AIDS and having many sexual partners.

I feel very strongly about some of our customs which make life more difficult for women, such as wife inheritance and the fact that a husband’s family inherits the widow’s possessions even after a legal marriage. Women need to know there are laws which govern a divorce. The practice of bride price means that, if her family needs the money, a woman cannot avoid getting married to someone she knows is sick. When men have more than one wife they just chase a sick wife away.

There are also cultural practices which do not help women. They need to have access to good food which is difficult. For example, a pregnant woman is not allowed to eat eggs. Another problem is that many people spend large amounts of money to counteract bewitching, which they believe is the cause of sickness.

I will continue to help women write their last testaments and help them provide for their children. I believe that each of us can live positively with AIDS and that we don’t have to give in to unjust practices.

Anna Kitwala, with Sister Veronica Schwyen, Mwanza, Tanzania.

RESOURCES

AIDS, health and human rights: an exploratory manual links public health and human rights issues with HIV. Available for Swiss francs 20.00 from International Federation of Red Cross and Red Crescent Societies, PO Box 372, CH 1211 Geneva 19, Switzerland.

Challenges of going public: commonly asked questions and answers to people going public and Stepping out in the open. Available from PLI, PO Box 10446, Kampala, Uganda (contact PLI for price information).

Empowerment through enterprise provides guidelines for NGOs to support self-employed people. Available for £11.95 from Intermediate Technology Publications, 103-105 Southampton Row, London WC1B 4HH, UK.

Income generation schemes for the urban poor provides basic guidelines for NGOs starting income generation projects. Available for £8.95 from Oxfam Publications, 274 Banbury Road, Oxford OX2 7DZ, UK.


For more information about groups for people living with HIV and AIDS contact Global Network of People Living with HIV and AIDS (GAP+), PO Box 11726, 1001 GS, Amsterdam, The Netherlands and International Community of Women living with HIV & AIDS, PO Box 2338, London W8 4ZG, UK.

New resources

Africa against AIDS is a catalogue of African AIDS education materials in English, French and Portuguese. Available free for developing countries (£10 elsewhere) from AHRTAG.

Broadening the front describes NGO responses to HIV and AIDS in India. Available for £2.75 from TALC, PO Box 49, St Albans, Herts AL1 5TX, UK.