Worldwide, many people infected with HIV or who have AIDS are denied their human rights. Some are put into quarantine, imprisoned, or forcibly tested, as described by Dominic d’Souza on page 3. People have been deported from, or denied entry into countries. They have been refused housing, employment or schooling, or have not received care and treatment, and details about them have not been kept confidential. There is also concern that people participating in research into, for example, new drugs, have not been adequately informed about possible risks. People who are believed to be infected or at risk of infection, or who associate with people who are infected, have also been subjected to these abuses.

A major challenge of the AIDS epidemic is to stop these abuses. Respecting, promoting and protecting human rights are inseparable from efforts to prevent HIV infection and to provide care to infected people. This issue of AIDS Action describes how organisations and individuals have worked to achieve human rights in the context of HIV/AIDS.

Some people’s human rights are already threatened or abused by governments, health care institutions, employers, colleagues and by members of the communities in which they live.

Double discrimination

Often people are unfairly treated because of fear, ignorance or prejudice, or may experience discrimination because they are poor, disadvantaged or marginalised. Many of these people are also among the most vulnerable to HIV infection, and associated stigma. They include, for example, women, children, the poor, street youth, prisoners, the homeless, sex workers, men who have sex with men, injecting drug users, migrants and refugees.

Education is a key factor in helping people to overcome their fears, ignorance and prejudice, and also to reduce the spread of infection.

Governments sometimes wrongly believe that the AIDS epidemic can be controlled by limiting the freedom of individuals with HIV. But depriving people of their rights harms everyone because it interferes with efforts to prevent HIV infection.

Fear of discrimination drives people underground: they often deny that they might be infected, or are reluctant to seek counselling or treatment. This increases individual suffering, and reduces the effectiveness of prevention and care programmes.

In some countries, changing the law has prevented human rights abuses related to HIV infection or AIDS. Concern for human rights has stimulated the development of community and service groups. Many have campaigned to raise the awareness of the public and of policy makers about the importance of human rights, as well as defending the individuals who are most vulnerable to abuse.

Many people now have more access to accurate information about preventing AIDS. There is also general agreement that people should not be denied housing, employment or education because of HIV infection. Unfortunately, such successes are not universal. The challenge is to ensure that everyone, everywhere, is treated as we ourselves would wish to be treated.

Special issue on human rights:

- Access to health care for people with AIDS
- Human rights and homosexuality
- Campaigning for the rights of children and young people

AHRTAG

Appropriate Health Resources & Technologies Action Group Ltd
Human rights and HIV/AIDS

Strategies for action

Promoting and protecting people’s rights are inseparable from efforts to prevent AIDS. This article summarises how governments, international organisations, community groups and individuals can work for human rights.

Promoting human rights in the context of HIV/AIDS means:
- encouraging people to respect each other’s rights, and to treat others as they themselves would wish to be treated;
- making sure that education, and access to health care are available to everyone;
- educating people to help them overcome their fears, ignorance and prejudices that lead them to abuse the rights of others.

Protecting human rights means:
- supporting and defending people whose rights are threatened or abused;
- remedying and compensating for abuses when they occur;
- working to change the conditions of poverty, powerlessness and dependence that make people vulnerable to abuse of their rights.

The law, courts and tribunals

The law is the main way in which human rights can be promoted and protected. Legislation can establish standards in society, deter people from going against them, and encourage others to claim their rights. Unfortunately, some of these laws unjustifiably limit the human rights of people with HIV infection or AIDS. For example, several countries require that people with HIV should be isolated, and the compulsory screening of prisoners and immigrants. In some, laws compel sex workers to be tested for HIV and STDs at regular intervals: they are detained, or otherwise prevented from working, if found to be HIV-positive. Injecting drug users are another very vulnerable group, liable in many countries to arrest and compulsory testing.

Other laws, however, protect against such abuses, by prohibiting both discrimination against people with HIV infection or AIDS, and testing as a requirement for insurance or employment. Laws protecting confidentiality help to prevent stigma, as well as guaranteeing people’s right to privacy. For example, in some African countries people are worried about giving blood because they know it will be tested for HIV antibodies. They fear that news about a positive test result will spread, and that they will be stigmatised as AIDS victims.

What are human rights?

Everyone is entitled to certain rights which have been defined in international law. The most famous example of this is the Universal Declaration of Human Rights. Governments have pledged to respect and implement these rights. Some rights are ‘absolute’ and, although they are not always respected by governments, no one should ever be deprived of them. These include the right not to be subjected to torture or to cruel, inhumane or degrading treatment or punishment. Other rights – to privacy and to free movement – may sometimes be legitimately restricted by governments. People are also entitled to an adequate standard of health care and education, and to employment, but these may be limited by a country’s economic resources.

Another important concept is equal rights. This does not mean that everyone must be treated the same. Some people may have to be treated more favourably because, for example, they are poor, ill or disadvantaged. However, treating people differently is wrong, if for example they are treated unfavourably, and this cannot be justified. This will often be the case when people are discriminated against only because of their sex, ethnic or national origin, religion, sexual orientation, age, disability or illness.

Education about AIDS is essential – both to help people reduce the risk of infection, and to help them deal with their fears, anxieties and prejudices.
Courts and tribunals have punished human rights abuses, and these decisions help prevent future abuses. But it can be difficult to use the law to protect human rights. People may have to say that they have HIV/AIDS, and this may expose them to further stigmatisation or discrimination. Some people, particularly those who are ill, may be discouraged by fear of expensive legal proceedings, or frustrated by delays in the process. Making sure that legal procedures are confidential, and that accelerated and low cost services are available, is important.

International organisations
The United Nations, the World Health Organization, the International Federation of Red Cross and Red Crescent Societies, Amnesty International, and many others, have supported the promotion and protection of human rights in relation to HIV/AIDS. Their recommendations and reports provide important standards.

Governments
Some governments have adopted policies which prohibit discrimination against people with HIV infection or AIDS in government workplaces. Other policies prevent the routine isolation of prisoners with HIV infection or AIDS, or the exclusion of infected foreigners seeking entry into these countries. Adopting such policies sets a good example for businesses, organisations, institutions and individuals outside government.

Governments can also work to correct the reasons for human rights abuses and to reduce the vulnerability of people whose rights are abused. Examples include: affirmative action policies which seek to, for example, end discrimination against women or disabled people; social and welfare assistance programmes; recognition and funding of community groups and service agencies; public education; and providing appropriate resources for HIV/AIDS programmes.

Community groups
Many of those working in AIDS prevention are supporting human rights, by giving people the opportunity to protect themselves and others from HIV exposure, through education, and by providing access to confidential counselling and HIV antibody testing, condoms, contraception, or injecting equipment.

Some are groups also providing care and treatment for people who are infected with HIV or who have AIDS. Others have demanded and won greater equality in access to and standards of care. This includes access to improved health services and information about AIDS, condoms, and injection equipment for prisoners or injecting drug users.

Community groups and service organisations, through campaigning and activism, can also inform people about their rights and about how to protect them. Often their work goes beyond

Continued on next page

Challenging discrimination in India

'In February 1989 I was asked to report to the nearest police station. Once there I was taken to the government hospital and given a physical examination in front of six armed policemen. I was very frightened, and no one would tell me what was going on. Then a nurse showed me my name written in a register. Across my entry was written the word 'AIDS'. This was how I discovered I was HIV-positive.

From the hospital I was taken by ambulance under armed guard to a former TB sanatorium. The medical staff there knew nothing about HIV, and were very unsympathetic: they treated me as though I could contaminate them. The authorities used the state Public Health Act to keep me in isolation.

My family, friends and fellow villagers were extremely supportive, and with the help of a non-government organisation we challenged the authorities in court. Eventually, the court decided that HIV-positive people should be allowed to live and work as everyone else in society. But they also ruled that it was still legal for authorities to isolate people if necessary.

'Human rights are part of everyone’s daily lives.'

Throughout my 'trial', the press publicised the story in an insensitive and sensational way, causing both me and my family great pain. After my release, I went back to my job. To add insult to injury, after six months I was told by my employer to take early retirement because I was HIV-positive.

Human rights are too often viewed as the concern of legal experts, rather than as a part of everyone's daily lives. It is intolerable that people who are already suffering from a distressing and possibly fatal illness should have their problems compounded by discrimination and prejudice.

I, for one, will no longer keep quiet when I hear about people in Thailand being arrested and confined because of their HIV status or when drug users in India are tortured because they tested HIV-positive. I will continue to raise my voice in the hope that the world listens, and that it hears the message loud and clear.'

Dominic d'Souza died in May this year. We print this personal testimony in tribute to his courage, and his commitment to promoting human rights in the context of HIV/AIDS. He was a founder member of the self-help group, Positive People (Pinto Addo, Verla Para, Bardez, Goa 403510, India) which aims to provide counselling and information to people with HIV/AIDS, and to promote human rights through education campaigns and lobbying national policy makers, and which is supported by the Dutch organisation HIVOS.
Most women are disadvantaged legally, economically and socially. This can limit their capability to protect themselves from the risk of HIV infection, and makes them vulnerable to the social and economic effects of HIV/AIDS.

Key issues
- Lack of access to education and health care (including sexual and reproductive health care).
- Lack of opportunity for regular, paid employment, which means women are often dependent on male partners for their own and their children’s survival.
- Women have little power in deciding when they have sex, because this decision often rests with their partners. Rape, sexual abuse and harassment are common.
- Women are usually expected to be faithful, but it is often accepted that men will have more than one sexual partner.
- Divorce and inheritance laws frequently discriminate against women.
- Women have been blamed for the spread of HIV which has led to more discrimination and stigma.
- Selling sexual services, one common way for women to earn money in the absence of other income, can carry a high risk of infection.
- Few research studies have focused on women, which means that less is known about how HIV/AIDS affects them.
- HIV-positive women have been pressured by doctors not to have children, or to be sterilised or to have an abortion. Health workers have refused to carry out abortions, or abandoned women to cope with childbirth alone.

Women are fighting back against abuses of their human rights. For example, in Uganda the Association of Women Lawyers (known as FIDA-U) gives legal advice and protection to women who have decided to leave their homes, or to stop having sexual intercourse with their husbands, because of the risk of AIDS. The group provides protection using national non-molestation and separation laws.

Progress in Uganda has also been achieved through local government committees, which include women’s affairs representatives. Recently over 300 of these representatives, from a district where AIDS is having an enormous impact, passed this important resolution: ‘If our husbands go with other women, we should be protected by law so that we can refuse sexual relations with our unfaithful husbands, but remain in our homes enjoying the same rights and privileges.’ This policy has won the support of the committees’ wider membership and is being put into practice at the village level.

From a paper by Eva Magambo, AIDS Programme, Experiment in International Living, PO Box 9007, Kampala, Uganda.

People with HIV/AIDS often experience stigma, and also do not get the medical care they need. AIDS Action reports on how a Red Cross home care project is approaching these issues.

Everyone is entitled to adequate health care. However, many people do not seek health care because of poverty, lack of transport, mistrust of the health services or because it is not a priority. People with AIDS may be unwilling to go to a clinic because they are frightened to reveal their HIV status, or may not realise that their illnesses can be treated. They may be discriminated against or badly treated by health workers. In addition, the increasing number of people with AIDS means that hospitals cannot look after them all.

**Care in the community**

Effective community based care programmes can help to increase people’s understanding of HIV/AIDS, and to reduce stigma. For people with AIDS, staying at home means continuing to live as normal a life as possible, without being separated from their families.

The Rwanda Red Cross Project Info-SIDA, with support from the Norwegian Red Cross, is helping to make sure that people with AIDS-related illnesses receive basic nursing care at home. The project has developed training materials on care for chronic illnesses related to AIDS, and TB and malaria. Two Rwandan nurses trained Red Cross volunteers (mostly teachers or community workers) to teach carers how to:

- recognise and understand the common symptoms of chronic illnesses;
- keep the patient and their surroundings clean;
- provide a diet that is as nutritious as possible;
- prevent transmission of disease, including HIV;
- treat skin and mucous membrane infections, fever, diarrhoea, cough and deal with confusion;
- relieve pain and discomfort;
- care for a patient who is dying.

The volunteers were supplied with AIDS information materials, dressings, soap, gentian violet, simple pain remedies, oral rehydration salts and vaseline. These were for demonstration only; families have to buy their own supplies. The project is discussing whether or not to provide supplies free of charge, although there is concern that this would make it too expensive in the long term.

Many families live in very remote villages where health services are not available, and they have little money to buy food and medicines. Although most families had initially sought treatment for the sick person, they are now caring for them at home with no medical support. Over half the family care givers were women living in the same house as the sick person.

At first, several of the volunteers offered their services only to families looking after people with AIDS. But the volunteers found that some families refused visits until the service was available for a person with any chronic illness, not just AIDS. This, and the fact that AIDS is only one of many diseases for which people need care, shows the importance of reaching families caring for anyone with chronic illness.

After training, the nurses visited each volunteer in his or her home village, and three months later the volunteers met as a group again for a follow-up session. The project was evaluated after six months through interviews with ten of the volunteers, as well as with 24 families whom they had taught. The results showed that volunteers can be trained to teach basic nursing skills to families, and that the families themselves felt that the visits were emotionally supportive and encouraging.

**Coming to terms with AIDS**

Many people in Rwanda with AIDS do not know their diagnosis. Even in the rare cases where HIV testing is preceded and followed by appropriate counselling, people are reluctant to tell even their families, because the fear of stigma is very strong. The volunteers discussed their own anxieties about AIDS, and the importance of confidentiality. For them, talking with an invited HIV-positive speaker was a very valuable aspect of the training.

They also learnt about helping people in the community overcome their own fears and prejudices. As part of the training, this situation was described to the volunteers: ‘John is ill, and his wife is earning money for the family through selling tomatoes. But people have been saying that he has AIDS, and have stopped buying her produce because they think they will catch the illness.’

Then the volunteers discussed how they would respond to people talking like this. Suggestions included:
- explaining the facts about AIDS;
- showing that they are not afraid by buying and eating some of the tomatoes;
- asking them to imagine being too ill to work, or being rejected;
- encouraging them to think of ways to help John and his family.

Helen Schietinger and Bodil Lawrence Ravn, Project Info-SIDA, Croix-Rouge Rwandaise, BP425, Kigali, Rwanda.

A booklet on teaching home nursing care will be published by the Norwegian Red Cross later this year. Details will be published in AIDS Action.
On the frontline

Aart Hendriks explains why respecting same-sex relationships is essential to AIDS prevention, as well as to human rights.

In every country, some people have same-sex relationships: men have sex with men, and women with other women. The fact that homosexuality is less visible in some countries does not mean that it does not exist. In many countries having sex with someone of the same gender is illegal, and people are subjected to harsh penalties. Homosexual men (gay men) and women (lesbians) are discriminated against by governments, employers and the wider community.

**Driving AIDS underground**

Men who have sex with men were often the first to be diagnosed with HIV/AIDS. The linking of homosexuality with AIDS (despite the fact that, worldwide, over 80 per cent of infections are in heterosexual people) has led to new fears and increased discrimination. Governments have introduced repressive measures: men who have sex with men have been imprisoned, or forcibly tested without counselling.

Where homosexuality is illegal, or its existence is denied by governments, people may have great difficulties in forming stable relationships and in obtaining appropriate health care and advice. This means that they are not able to protect their own health, nor that of others, leading to the risk of further spread of HIV.

**Radical response**

By the mid 1980s, gay organisations throughout Latin America had started to develop AIDS-related activities, in response to the effects of the epidemic and increasing prejudice against gay people. For example, in Mexico, the police arrest people whom they think are gay, rob and blackmail them, and test them for HIV without their consent.

Gay organisations were among the first to provide basic services, including treatment for opportunistic infections. The health services are still not prepared for AIDS and it is common for hospital staff to refuse to look after or to carry out surgery on patients with AIDS. Some refuse to allow patients to die in hospital, but send them home, where their families may have no means to care for them.

Gay men, lesbians and bisexual people are members of the wider community. Fighting for the rights of gay and bisexual people affected by HIV/AIDS is part of fighting for the rights of everyone. But our contribution towards fighting AIDS has not resulted in full recognition for the rights of men and women to have same-sex relationships, and we are still campaigning for an end to discrimination.

Juan Jacobo Hernández, Colectivo Sol, AP 13-320, Mexico DF 03500.

**From intolerance to respect**

Many people have been more open about their sexuality since the AIDS epidemic began. They feel that the price of silence and doing nothing is too high, in terms of the risk of infection and death, and prefer to work with others fighting AIDS, even though they risk experiencing more prejudice.

The epidemic has strengthened solidarity amongst lesbians and gays. During the past few years membership of the International Lesbian and Gay Association (ILGA) has grown to include new groups in Asia, Africa, Latin America, the Caribbean and Central and Eastern Europe.

Increasingly it is being argued that people should not be discriminated against on the grounds of their sexual orientation. In 1991 Amnesty International, represented in almost every country, declared that no one should be imprisoned or prosecuted because of their sexual orientation. The World Health Organization has now removed homosexuality from its International Classification of Diseases (to be effective from January 1993). Recognising that lesbians, gay men and bisexual people are entitled to the same rights to privacy, information and health care as everyone else is part of fighting the epidemic effectively.

Many governments and international organisations, such as WHO's Global Programme on AIDS, are starting to recognise the important role that lesbians and gay men have played and continue to play in the fight against AIDS.

The fight must be continued, with a strengthening of the coalitions between lesbian and gay groups, other NGOs and government agencies, and this must happen in parallel with steps towards fully respecting the human rights of people involved in same-sex relationships.

Aart Hendriks, legal researcher, Utrecht University, Utrecht, The Netherlands.

ILGA, Information Secretariat, Rue Marche au Charbon 81, B-1000, Brussels, Belgium.
Rights of young people and children

Taking health promotion on to the streets!

Ana Filgueiras describes the links between campaigning for children’s rights, including access to health care, and preventing AIDS.

In Brazil, until 1990, the authorities could legally arrest a child found alone in the streets, and put them in prison-like institutions. Their crime? To be poor, usually black and living on the streets.

Changing discriminatory laws
The Brazilian Centre for the Defense of the Rights of Children and Adolescents (SOS Criança) was set up a few years ago with the aim of changing this legislation. Together with other non-government organisations, SOS Criança drew up new legislation, lobbied politicians and policy makers, and publicised the issue at the community level and in the media.

In 1990 the battle was won: a new Child and Adolescent Statute, based on the International Declaration of Children’s Rights, was made law. Lawyers volunteered their services to SOS Criança, making sure that young people had access to legal support, so that the new law could be put into practice.

Poverty and violence
AIDS has added to the difficulties of young people living on the streets. In 1988, using a strategy similar to the one above, SOS Criança started to work with key organisations and individuals, including the ministry of health, street educators and the children themselves, to draw up an HIV prevention strategy for street children.

As well as being threatened with violence and police arrest, these children lack a basic human right – access to health care. Public health services in Brazil do not reach the 40 per cent of the population who live in absolute poverty, which includes young people on the streets.

Preventing AIDS is seen by SOS Criança to be just a part of promoting better health and providing overall health care. Educational activities will not work if children do not have access to treatment, or to basic needs like food and shelter.

SOS Criança does not employ doctors, because it is not the role of non-government organisations to take over the state’s responsibility to provide basic health care. But how can the public clinics, staffed with underpaid professionals and lacking basic equipment meet the needs of street children?

Supportive health workers
Meetings were organised with different health professionals, involving those most sensitive to the problem in setting up a referral system. Little by little we made progress. One day a doctor would make the appointment timetable more flexible, and the next a nurse would come to help develop counselling sessions.

This support has helped to change the attitude of other health professionals towards these young people. Now a child on the streets can be told: ‘Go to this hospital, and you will be well treated.’

Our street educators try to give the children themselves an awareness of their right to use public health care facilities. The educators work every night on the streets, giving advice and counselling and assessing the children’s health problems. In the mornings and afternoons the educators go with them to the clinics or follow up with other types of referrals.

SOS Criança also has an ongoing prenatal care programme for girls and an STD diagnosis, counselling and treatment programme, which includes HIV/AIDS.

How many young people does SOS Criança reach? The answer is not only to do with the numbers seeking health care, but also how many clinic doors are open to them.

More and more young people, not just those living on the streets where SOS Criança works, but others in poor communities, are using the service. It is called ‘Health Maloca’, because the children call their makeshift homes – shelters made of cardboard and newspaper – ‘malocas’. The name also symbolises that these young people need to find their own ways of taking more control over their bodies and lives.

Ana Filgueiras, Centro Brasileiro de Defesa dos Direitos da Criança e do Adolescente, Rua do Livramento 158, CEP 20010, Rio de Janeiro, Brazil.
Breastfeeding and HIV

Recent research confirms that it is possible for HIV to be transmitted through breastfeeding. However, the vast majority of infants breastfed by HIV-positive mothers do not become infected through breastmilk.

WHO and UNICEF have published the following recommendations:

- Breastfeeding should continue to be protected, promoted and supported in every country, irrespective of HIV infection rates. Studies continue to show that breastfeeding saves lives, helping to protect infants against diarrhoeal diseases, pneumonia and other infections. Bottle-feeding is a major contributing factor in the 1.5 million infant deaths from diarrhoea each year.

- Where the primary causes of infant deaths are infectious diseases and malnutrition, infants who are not breastfed are at high risk of dying from these conditions. Breastfeeding should remain the standard advice to pregnant women, including those known to be HIV-positive. This is because a baby’s risk of becoming infected with HIV through breastmilk is likely to be lower than dying from other causes if deprived of breastfeeding. The higher a baby’s risk of dying during infancy, the more protective breastfeeding is and the more important it is that the mother be advised to breastfeed.

Women whose particular circumstances would make alternative feeding an appropriate option may wish to find out their HIV status to help guide their decision about breastfeeding. Voluntary and confidential HIV testing, with pre- and post-test counselling, should be made available where possible and affordable.


AIDS Action will be publishing more information on HIV and breastfeeding in a future issue.

Conference USA boycott

This year’s international conference on AIDS was scheduled to take place in the USA. Instead, it was moved to the Netherlands. This followed protests from human rights and AIDS activists throughout the world against discriminatory USA entry restrictions. Along with a few other countries with similar policies, the USA has been widely criticised by governments and NGOs for trying to restrict people with HIV/AIDS entering the country.

The conference summary and recommendations, as well as a longer report (useful for academic and research institutions and libraries) will be available from Harvard AIDS Institute, 8 Story Street, Cambridge, MA 02138, USA.

AIDS prevention award

AIDS Action readers are invited to nominate candidates for the 1992 NORAD award for outstanding work in the prevention of AIDS in a developing country. For information on how to nominate and a form, contact Division of Health, NORAD, PO Box 8034 Dep. 0030, Oslo, Norway. Closing date for nominations is 1 September 1992.

Community commitment

On 1 December 1992, World AIDS Day (the annual international day of action against AIDS), millions of people will be taking part in events that highlight the commitment to fighting AIDS at the community level. Involving the whole community is crucial to successful initiatives — everyone, everywhere, needs to receive information that makes sense to them about how to prevent infection, and how to support people living with HIV/AIDS.

For more information, contact: World AIDS Day, GPA, World Health Organization, 121 Geneva 27, Switzerland.