

CHAPTER 2

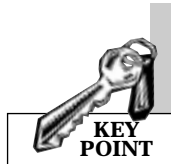
HIV/AIDS, power  
and discrimination



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## 2.1.1 PREJUDICE AND DISCRIMINATION

Because the first cases of **Acquired Immune Deficiency Syndrome (AIDS)** were discovered amongst **gay men** in the United States of America (USA), there was a misunderstanding that AIDS was a disease that only affected gay people. It caused a new wave of **prejudice** and **discrimination** to develop against gay men and **lesbians**. Some newspapers even described AIDS as a 'gay plague'. This was the origin of many of the myths and misunderstandings about HIV.

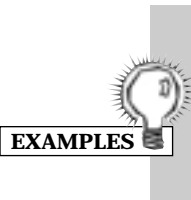


### **SEX THE MAIN RISK**

*After scientists learnt more about how HIV caused AIDS, they explained that it was types of sexual behaviour – not **sexual orientation** – that placed a person at risk of infection.*

*For more information about HIV transmission, see 1.3 on page 13.*

Many newspapers, individuals and even governments continued to spread the idea that HIV/AIDS was mainly something that affected gay men and other 'risk groups'. Some countries passed harsh laws that they thought would protect society from these 'risk groups'.



### **RESTRICTIVE LAWS ON HIV/AIDS**

- *Laws making it compulsory for sex workers or gay men to be tested for HIV.*
- *Laws that made a negative HIV test a condition for entry into that country.*

These laws contributed to the prejudice around HIV and often violated people's human rights. They did not help to prevent the spread of HIV.

## 2.1.2 THE NEED FOR EDUCATION

By the middle of the 1980s, HIV and AIDS were becoming common in countries all over the world. AIDS was no longer seen as an illness that would affect only a few people. It started to become clear that, unless millions of people were quickly taught about how to avoid HIV, it would become an **epidemic**.

In most countries in the industrialised world, ordinary people and governments joined hands to warn people about how to stop HIV. As a result, many lives have been saved and only a small percentage of the total population has been infected.

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### 2.1.3 THE EFFECTS OF POVERTY

But in poor countries or countries where there have been long wars or **oppression** (such as in South Africa), millions of people were not taught how to protect themselves. It is much harder to teach people about HIV if they cannot read, or do not have television or radios.

We have also learnt that changing sexual behaviour to prevent HIV infection is very difficult for people who live in desperate poverty.



#### EXAMPLES

#### **POVERTY AND CHANGING SEXUAL BEHAVIOUR**

- *If you are a refugee or a migrant worker thousands of kilometres from home, sex may be one of the few things you can do to enjoy yourself.*
- *If you are a woman or girl in a family without any income, selling sex is often the only way to get money to buy food.*

*For worldwide HIV/AIDS statistics and more on the link between HIV/AIDS and poverty, see 1.2 on page 11.*

These are some of the reasons why, by December 2002, Sub-Saharan Africa had 29,4 million adults and children infected with HIV. This is 70% of the world's total number of people living with HIV, compared with North America, which has 980 000 people with HIV. In 2002 2,4 million people in Africa died of AIDS.



#### KEY POINT

#### **POVERTY HELPS SPREAD HIV**

*Poverty cannot cause HIV or AIDS. But we have seen that poor people are definitely more at risk of HIV infection, and of developing disease more quickly.*



### KEY POINTS

#### PROTECTING PEOPLE MOST AT RISK

- Those who are least powerful in society, are most at risk of HIV infection.
- South Africa's Constitution and Bill of Rights protect people from discrimination and abuses of power, and are important weapons in the fight against HIV/AIDS.

For more on the Constitution and the fight for equality, see Chapter 4 on page 63.

The HIV/AIDS epidemic is often linked to who has power in society. Usually, it is the least powerful people who are most at risk:

- Because of widespread poverty, people in Africa or Asia are more likely to be infected with HIV than people in the USA or Europe.
- Black people in South Africa (who have faced oppression and discrimination) are more likely to be infected than white people (who have wealth and power). Poor people in the USA are more likely to be infected with HIV than richer people.
- Women (of all races) are still treated by most men in South Africa and other African countries as second-class citizens. Many women do not have power to negotiate **safer sex**. Many men are still not willing to use condoms with their sexual partners, and there are few female-controlled methods of HIV prevention (eg **microbicides**).
- Men who have sex with men are especially **vulnerable** (open to abuse) because they are **marginalised** in most societies. In many countries **homosexual sex** is illegal, meaning that gay men are denied information about safer sex.

From all these examples, we can see that the struggle for **equality** for all people is a very important part of our efforts to cut down the rate of new HIV infections. Fighting for equality means fighting against discrimination of women, gay men and lesbians. But it also means improving the social and economic conditions of millions of people to help them to gain full control over their lives.



*The social and economic conditions of people must be improved to help them gain full control over their lives.*

Language is also a tool of power.

In South Africa, we can still remember the racist language that was used by the apartheid Government. Words made people feel powerless.

### **THE POWER OF RACIST LANGUAGE**

EXAMPLE



Words like ‘non-European’ and ‘non-white’ were used in a way that made people feel that they were a ‘non-something’, rather than people who were proud to be ‘black’ or ‘African’.

The same is true about the words that are often used around HIV and AIDS. People who are living with HIV or AIDS do not like to be described as ‘AIDS victims’, ‘sufferers’ or ‘patients’. We should avoid words that attach blame or moral judgements to an illness, or suggest that people are powerless.

For more on the different stages of HIV, see 1.6 on page 22.

### **THE NEED FOR SENSITIVE LANGUAGE**

- When talking about people with HIV or AIDS, the emphasis is on the fact that people are living with the illness. This is why we talk about “people living with HIV or AIDS” or “people with HIV or AIDS”.
- When we describe things like programmes or policies, we talk about “workplace HIV/AIDS policy” – here we combine ‘HIV/AIDS’. But when we are referring to people, we do not say “a person with HIV/AIDS” – rather we say “a person with HIV or AIDS”, because the two conditions are medically different.

KEY POINTS



### **USING LANGUAGE SENSITIVELY**

People’s personalities are not defined firstly by HIV or AIDS, but by their natural characteristics. That is why we do not say “Sipho or Alice is an HIV positive person”, but Sipho or Alice is living with HIV or AIDS. They are people first!

EXAMPLE



## Why are people with HIV or AIDS victimised?

The fears of people and politicians have led to a lot of discrimination and victimisation against people living with HIV or AIDS.

### 2.4.1 EARLY RESPONSES IN SOUTH AFRICA

In South Africa, people at first linked AIDS to gay men. But when a study in 1987 showed a relatively high level of infection amongst Malawian gold miners, the blame shifted to people from other African countries. Later many people thought AIDS was a 'white' disease. Today many white people think AIDS is a 'black' disease.

Sometimes, people in the apartheid Government used to blame AIDS on 'terrorists' coming from other African countries. As a result, they did very little to try and teach our country about HIV/AIDS.

Because of these kinds of attitudes, many years were wasted and HIV began to spread very fast among all South Africans. Between 1990 and 2003, the level of HIV infection among pregnant women rose from less than 1% to over 24%.

In 1997, a National HIV/AIDS Review found that there was "widespread and systematic abuse of the basic human rights of people with HIV/AIDS in all 9 Provinces". It proposed that there should be "a concerted effort to protect human rights, counter discrimination and reduce stigmatisation" (negative labelling):

*“We shall work together to care for those living with HIV/AIDS and for the children orphaned by AIDS. They must not be subject to discrimination of any kind. They can live productive lives for many years. They are human beings like you and me. When we lend a hand, we build our own humanity, and we remind ourselves that, like them, each one of us can become infected.”*

From: Declaration by President Mbeki, October 1998

### 2.4.2 CONTINUED FEAR, IGNORANCE AND CONFUSION

In South Africa today, there is a high level of 'awareness' about HIV/AIDS. But awareness is not the same as knowledge and understanding. Many people still do not understand how HIV is transmitted between people or what HIV infection does to our **immune system**.

Most people still think of AIDS as an automatic 'death sentence'. They are not aware that there are drugs that can attack HIV and prevent many of the illnesses it causes. Other people still want to deny that HIV causes AIDS, or that AIDS exists at all.

See the graph on pregnant women with HIV in 1.2 on page 12.



## CONFUSING MESSAGES

President Thabo Mbeki has publicly questioned the link between HIV and AIDS. This has caused a lot of confusion in people's minds, and AIDS educators say that when they run workshops now, they can see that the President's statements have set back years of education efforts about HIV and AIDS, and especially about the need for safer sex.



For more on the links between HIV/AIDS and poverty, see 2.1.3 on page 33.

This means that there is still a lot of fear and ignorance about HIV/AIDS:

- Fear causes people to act in ways that are irrational.
- It makes people reluctant to change the way they think and behave.
- It makes people afraid to talk about HIV and AIDS.

## 2.4.3 VIOLENCE AGAINST PEOPLE LIVING WITH HIV OR AIDS

### VIOLENCE AGAINST PEOPLE LIVING WITH HIV OR AIDS



- At the end of 1998, a woman called Gugu Dlamini was murdered by people in her community because she publicly **disclosed** that she was living with HIV.
- In 2000, a man in Soweto murdered his wife and father-in-law, and then committed suicide after he and his wife were **diagnosed** 'HIV positive'.

These are some of the reasons why Appeal Court Judge Edwin Cameron said that he was only able to disclose that he was living with AIDS because of his privileged access to treatment and employment, and the support and care of his family and friends. He explained:

“ For millions of South Africans living with HIV or AIDS, these conditions do not exist. They have no jobs, or their jobs would be at risk if they spoke about their HIV. They not only lack community support, but face grave personal danger if they do so. And, most importantly, they do not have access to proper medical care and treatment. For them, in a still hostile climate, the choices are strictly limited. ”



### THE EFFECTS OF FEAR AND IGNORANCE

The fear and ignorance surrounding HIV/AIDS often leads to discrimination and violence against people living with HIV or AIDS, their families and partners.

## 2.4.4 TYPES OF DISCRIMINATION CURRENTLY EXPERIENCED

Today, people with HIV still face many kinds of discrimination:

- Many people are refused employment or membership of employee benefit schemes.
- Insurance companies refuse to offer life insurance to people with HIV and banks often refuse bonds.
- Many people are refused proper health care and equal membership of medical aid schemes.
- Children and students with HIV, or of parents with HIV, are victimised at schools.
- Many people are tested for HIV in our hospitals without giving informed consent, or are told about their HIV status without being counselled.
- Breaches (breaking of) of confidentiality and privacy happen almost every day (eg disclosing someone's HIV status without their consent).

Many people are tested for HIV without giving informed consent. This is against the law.



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For more on the Constitution and the Bill of Rights, see Chapter 4 on page 63.

For more on the Employment Equity Act, see 7.2.3 on page 161.

Under the Constitution and laws such as the **Employment Equity Act**, many of these actions are **unlawful** and can be challenged. But the problem is that the majority of people with HIV or AIDS are poor and afraid – they do not know how to stand up for their rights or are afraid to be open about their HIV status.

### **PEOPLE LIVING WITH HIV OR AIDS – A VULNERABLE GROUP**

In *Hoffman v South African Airways* (2000), the Constitutional Court said this about people living with HIV:



“ They have been subjected to systemic disadvantage and discrimination. They have been stigmatised and marginalised ... Society’s response to them has forced many of them not to reveal their HIV status for fear of prejudice. This in turn has deprived them of the help they would otherwise have received. People who are living with HIV/AIDS are one of the most vulnerable groups in our society. ”

## How does discrimination help spread HIV?

Discrimination, stigmatisation and victimisation help the spread of HIV.

Discrimination has made it easy for people to blame others without protecting themselves. People like to believe that HIV infection only happens to gay people, sex workers and 'people who sleep around'. Many people think that if you are not gay or a sex worker, you are 'safe'. This is not true.



### **SEX IS THE RISK**

*Types of sexual behaviour – not whether you are gay or straight, black or white – put you at risk of HIV infection.*

South Africa has about 4,74 million people with HIV, but most do not know because they have not had an HIV test. This means that many people unknowingly pass HIV on to other people.

Effective HIV prevention and treatment depends on people wanting to have an HIV test – and finding out if they are infected with HIV. But for as long as people with HIV continue to face discrimination, people will be afraid to volunteer for an HIV test.

Similarly, if people with HIV or AIDS continue to be discriminated against in the lack of access to treatments that can help to keep them well, they will see no purpose in having an HIV test.

Effective prevention and treatment also depends on people being more 'open' about HIV and AIDS. It depends on people not being afraid to tell their lovers, friends, family and even colleagues at work. When people feel confident enough to come forward freely to tell others about their HIV status, ignorance and misunderstanding about HIV and who is affected will start to break down.





Since 1994, South Africa has moved away from a *culture of discrimination* towards a *culture of rights*. We have moved from a time in our history when the legal system was used as a weapon against the majority of people to a time when the legal system can be a tool to protect people.

But if people do not know about their rights, they will not be able to protect themselves. In South Africa, several organisations have campaigned to educate society about the rights of people living with HIV or AIDS.

### **ORGANISING CAMPAIGNS AND EDUCATION ON HIV/AIDS**

- The National Association of People Living with HIV/AIDS (NAPWA) has members all over South Africa and is mobilising people with HIV to join an organisation that represents their interests.
- The Treatment Action Campaign (TAC) is fighting to improve access to treatment for people with HIV and to raise awareness and understanding about options for treatment.
- The AIDS Consortium is an umbrella organisation of over 1000 organisations. It has widely publicised a Charter of Rights on AIDS and HIV.
- The AIDS Law Project (ALP) and AIDS Legal Network (ALN) provide training, advice and legal assistance to people with HIV. They have helped to draft and promote policies and laws that are aimed at preventing discrimination. Many of these laws and policies are discussed in this manual.



For contact details of these and other organisations, see R8 on page 483.

For the Charter of Rights on AIDS and HIV, see A1 on page 491.

For the Department of Health's HIV/AIDS & STD Strategic Plan and the UNAIDS Guidelines, see References and resource materials on page 44.

For more on recent amendments to the UNAIDS Guidelines, see Introducing the manual on page v.

The need to protect and promote the human rights of people with HIV or AIDS has been widely accepted. It forms an important part of the Government's *HIV/AIDS and STD Strategic Plan for South Africa 2000–2005*.

In 1997, the United Nations Human Rights Commission and UNAIDS published *International Guidelines on HIV/AIDS and Human Rights*. These Guidelines have been sent to governments all over the world. In South Africa, they have been supported by the South African Human Rights Commission. This will help international efforts to stop discrimination.



## A new struggle

In 1994, the Department of Health adopted the slogan: 'AIDS – A New Struggle!' This means that we have to campaign for the rights of people with HIV or AIDS, in the same way that we fought racial discrimination, or victimisation of people because of their sexual orientation.

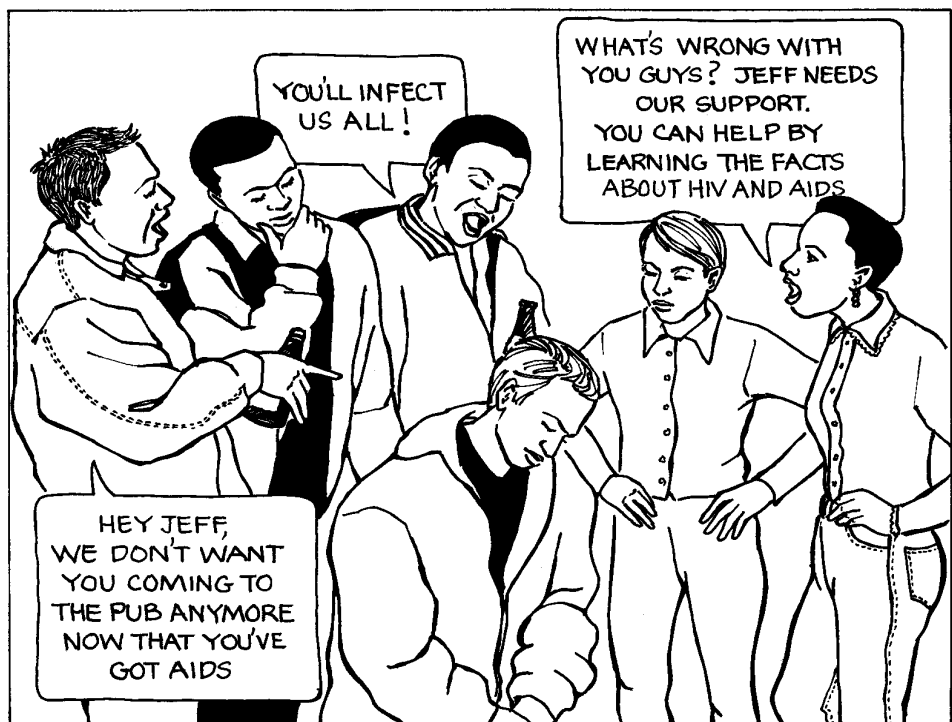
As you go through this manual, you will see that there are many areas where we need to campaign for the rights of people living with HIV or AIDS, such as the right to things like:

- **Non-discrimination**
- Effective treatments
- Better care
- More money for HIV prevention from government and employers.

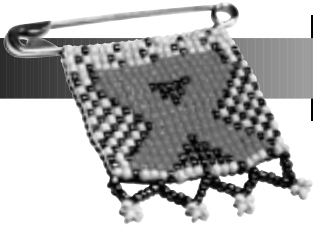
Most discrimination against people living with HIV or AIDS is based on ignorance and fear. That is why campaigns to educate people about HIV and AIDS are so important in all our communities, at our workplaces and in schools. Once someone knows the facts about HIV and AIDS, they have no excuse for treating another person badly because they think that person may have HIV or AIDS.

So, where discrimination does take place, especially when it is by major bodies such as hospitals or **public and private sector** employers, it is important to do everything we can to stop it.

Using the law is one way to fight this discrimination and to make sure that HIV prevention is successful.



*Most discrimination against people with HIV or AIDS is based on ignorance and fear.*



# Talking points



**1** President Thabo Mbeki's statements questioning the link between HIV and AIDS have caused a lot of confusion about how you get HIV and AIDS, and what it means to have HIV or AIDS.

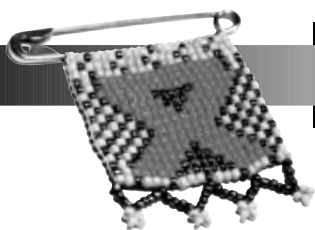
- *Have you experienced this in your work?*
- *How do you think this affects people's attitudes to HIV and AIDS?*
- *What do you think you can do about it?*

**2** "A lot of the discrimination and hate faced by people living with HIV or AIDS comes from people's fear and denial about what's happening to them ... in fact, how HIV/AIDS has changed all of our lives".

- *What do you feel about this statement?*
- *And what can we all do to change people's attitudes and actions?*

**3** People in South Africa are aware of HIV and AIDS. But most people are still not open about the disease. We still do not talk about HIV/AIDS openly in many schools, communities, churches, even hospitals. We do not talk about it when family members and friends die of AIDS, and most people living with HIV or AIDS are not open about their HIV status.

- *What do you think is stopping people from being open about AIDS?*
- *What can we do to increase openness around HIV/AIDS, while still respecting people's rights?*



# References & resource materials

## LAWS

Constitution of the Republic of South Africa Act, No 108 of 1996.

Employment Equity Act, No 55 of 1998.

## POLICY DOCUMENTS

Charter of Rights on AIDS and HIV (South Africa), AIDS Consortium, 1992.

Department of Health: HIV/AIDS & STD Strategic Plan for South Africa 2000–2005, May 2000.

## CASES

Hoffman v South African Airways, 2000 (1) SA 1 (CC).

## REPORTS, MANUALS AND OTHER USEFUL MATERIALS

AIDS Law Project (ALP) and Lawyers for Human Rights: HIV/AIDS and the Law – A Trainer's Manual, (First Edition), July 1997.

ALP: HIV/AIDS Current Law & Policy booklet 1: 'Know your rights and how to enforce them', July 2000.

AIDS Legal Network (ALN): ALQ – The AIDS Legal Quarterly.

Department of Health: National STD/HIV/AIDS Review Report, July 1997.

Human Rights Internet: Human Rights and HIV/AIDS – Effective Community Responses, 1998.

UNAIDS: AIDS Epidemic Update, December 2002.

UNAIDS / Inter-Parliamentary Union: Handbook for Legislators on HIV/AIDS, Law and Human Rights, 1999.

UN Joint Programme on AIDS (UNAIDS) and the UN High Commissioner / UN Human Rights Centre: International Guidelines on HIV/AIDS and Human Rights, January 1997, and September 2002.

## WEBSITES

AIDS Consortium: [www.aidsconsortium.org.za](http://www.aidsconsortium.org.za)

AIDS Law Project: [www.alp.org.za](http://www.alp.org.za)

AIDS Legal Network: [www.redribbon.co.za/legal](http://www.redribbon.co.za/legal)

Department of Health resources: [www.aidsinfo.co.za](http://www.aidsinfo.co.za)

Human Rights Internet: [www.hri.ca](http://www.hri.ca)

Treatment Action Campaign: [www.tac.org.za](http://www.tac.org.za)

UNAIDS: [www.unaids.org](http://www.unaids.org)