Disclaimer

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Stigma

Resource Pack

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Key to icons
used in the Stigma Resource Pack

idea icon
These sections elaborate on points made in the main body of the text in greater detail.

need to know icon
These boxes point out where to find more detailed information on particular issues.

handout icon
These are pages designed to be photocopied and handed out to participants in training workshops.

worksheet icon
These worksheets can be photocopied and handed out to workshop participants to complete.

notes to facilitator icon
These sections provide additional information that may be useful to the facilitator of an activity.
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Notes on words used in the Stigma Resource Pack

The use of the term PLHA

We have used the acronym PLHA for people or persons living with HIV and AIDS in order to shorten the text and make reading easier. We would, however, discourage the use of this acronym in workshops and instead promote use of the full phrase. In workshops where there are people who are living openly with HIV, ask them how they would like to be addressed.

The use of the terms HIV and AIDS or HIV/AIDS

There has been a growing trend to refer to HIV and AIDS separately to show that the two are different conditions and different experiences.

However sometimes it is appropriate to refer to HIV/AIDS as a single concept.

The Stigma Resource Pack uses the two interchangeably, according to the context.
1. Introduction

1.1 BACKGROUND

1.2 THE SIYAM’KELA PROJECT

1.3 WHAT IS THE STIGMA RESOURCE PACK?

1.4 HOW CAN THE STIGMA RESOURCE PACK BE USED?
Introduction

1.1 Background
The HIV/AIDS epidemic is a health problem in which the disease impacts not only on the physical health of individuals, but also on their social identity, making it different from most other fatal diseases. It was first associated with gay men, drug users and sex workers, individuals and groups already carrying the burden of societal stigmatisation. This created conditions to further marginalise and violate rights, and most importantly, to create perceptions that HIV/AIDS was a problem of ‘others’. In South Africa this had a further racial dimension. Although the epidemic was first identified in white gay men, it subsequently became seen as a disease of black people, reinforcing racism and notions that black people were immoral and promiscuous.

1.2 The Siyam’kela Project
Although much progress has been made in putting programmes in place to prevent new HIV infections and to mitigate the impact of the epidemic, including a comprehensive ARV programme, much of this work is hampered by stigma and discrimination associated with HIV/AIDS. The Siyam’kela Project, a joint project of the USAID-funded POLICY Project, the Centre for the Study of AIDS at the University of Pretoria and the Chief Directorate: HIV and AIDS and TB in the National Department of Health, was set up to explore and understand HIV/AIDS stigma in South Africa. The Project focused on three key areas which it believed could play a role in challenging stigma in South Africa: faith-based organisations and communities, government workplaces and the media. The Project also aimed to develop indicators of stigma which could be used in multiple settings and which would assist with measuring the impact of stigma mitigation efforts. Subsequently it has focused on developing interventions to address stigma, one of which is this resource pack.

1.3 What is the Stigma Resource Pack?
As a result of its experiences in working with HIV/AIDS stigma, the Siyam’kela Project felt it would be useful to develop a Stigma Resource Pack (SRP) to create awareness about stigma and inform stigma mitigation efforts. The SRP is aimed at trainers, opinion leaders, people living with HIV or AIDS (PLHA), community leaders/members, and anyone interested in getting information on HIV/AIDS stigma and how to reduce stigma in their field of work or community. There are a number of tools, which can be used for different purposes. We have tried to make the resource pack as flexible as possible. The SRP is also in line with the government’s intention to develop a national stigma strategy.

1.4 How can the Stigma Resource Pack be used?
Getting informed
The SRP provides information on stigma, advocacy and lobbying and human rights, and includes guidelines, recommendations and best practices. It is also possible to simply use the SRP as background reading and to get informed. Fact sheets are available to supplement workshops or as a stand-alone resource to hand out to individuals and communities who may want to take information home with them.
1. Introduction

Participatory learning

Trainers and workshop facilitators can use the SRP to encourage self-awareness and learning through stigma reduction workshops.

The workshop activities can be used to reduce stigma in the following ways:

- **Challenge attitudes and beliefs** - uncover how we create and can deal with stigma on a personal level, and learn how to do this with others.
- **Work with the media** - understand how the media contributes to stigmatisation, and learn how to work with the media to reduce stigma.
- **Advocacy and lobbying** - understand and use advocacy and lobbying in the context of de-stigmatisation.
- **Rights, policies and legal frameworks** - learn how to make the link between stigma, human rights and legal frameworks and guidelines, and how to use the legal framework to strengthen human rights.
- **Translate learning into action** - explore ways to actively challenge stigma on personal, community and global levels.

The workshop activities emphasise participatory and experiential learning. The idea is to get participants learning through doing – sharing feelings, concerns, and experiences; discussing and analysing issues; solving problems; planning; and taking action. Changing attitudes on stigma can only be achieved through a participant-centred learning process, not through listening to lectures.

Facilitators can select activities that best suit the needs of their groups, to create their own customised training or to integrate these exercises into an existing training programme. Examples of different workshop outlines are provided as a reference point.

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Lobbying and advocacy

If individuals and communities want to impact on stigma through challenging or getting the support of influential leaders (traditional leaders, community leaders and elected government officials) and institutions (schools, universities, faith organisations, hospitals and clinics), the section on lobbying and advocacy will enable them to explore ideas on ways to do this. There are also workshop activities on lobbying and advocacy.

**Doing community work**

Anyone who is interested in doing community work regarding HIV/AIDS stigma might be interested in using the Stigma Resource Pack. This could include holding community meetings to discuss stigma, setting up community bodies to fight stigma, developing door-to-door campaigns and setting up support groups for people affected by stigma. The Stigma Resource Pack has ideas and information which could support these interventions.

**Enforcing rights**

We know that people living with HIV or AIDS (PLHA) and those close to them may be affected by stigma and discrimination in all kinds of ways. They may wish to fight this through legal means, for example by laying a charge against someone who has refused them a service because they are HIV positive. The Stigma Resource Pack has information on how the law works and how to use it to enforce rights, rights which exist through our Constitution, our Bill of Rights and our laws.

**Using policy**

The SRP provides information on how policies and policy development can be used to challenge HIV/AIDS stigma, particularly in faith-based organisations, in media organisations and in workplaces in general.
2. What is HIV/AIDS stigma?

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What is HIV/AIDS stigma?

2.1 Is there a difference between stigma and discrimination?

Stigma can be described as an attribute or quality which significantly ‘discredits’ an individual in the eyes of others. This means that people will look at someone and have a negative attitude towards that person because of a certain quality or characteristic, for example the person is known or suspected to be HIV-positive.

Stigma allows PLHA to be treated differently from other people. This is what we mean by discrimination. Discrimination is a form of behaviour which results in unequal/unjustifiable treatment. It is important to note that stigmatising attitudes do not always translate into discrimination, but the effect of the negative attitude may still be damaging or hurtful to the PLHA.

There are two main types of stigma:

- **external stigma**
- **internal stigma**

External (or enacted) stigma refers to experiences of PLHA being treated unfairly and differently to everyone else. This discrimination may include oppression, rejection, punishment, harassment, blame or exclusion. It can also sometimes lead to violence against PLHA.

**Examples of external stigma are:**

- **Avoidance:** people avoiding PLHA or not wanting to use the same utensils.
- **Rejection:** people rejecting PLHA. This could be family members or friends no longer being willing to associate with the PLHA or it could be that a society or groups of people do not welcome PLHA.
- **Moral judgement:** people blaming PLHA for their HIV status or seeing them as immoral.
- **Stigma by association:** people who associate with PLHA are stigmatised because of their association.
- **Unwillingness to invest in PLHA:** PLHA may be marginalised within an organisation because of their HIV status.
- **Discrimination:** opportunities denied to PLHA, e.g. being denied employment; the denial of proper medical care or access to medical aid schemes; service providers denying services to PLHA, e.g. membership of employee benefit schemes or being denied insurance and home loans.
- **Abuse:** PLHA being physically or verbally abused.
- **Victimisation:** e.g. children and orphans who are infected or affected by HIV.
- **Abuse of human rights:** e.g. breaches of confidentiality such as revealing someone’s status to another without consent, or being tested without giving informed consent.

Internal stigma (felt or imagined stigma) is the way a person feels about themselves, e.g. shame, fear of rejection and discrimination.

**Examples of internal stigma are:**

- **Self-exclusion from services or opportunities:** PLHA not wanting to access services or not applying for work because they are afraid of being exposed as living with HIV.
- **Perceptions of self:** PLHA having low self-esteem as a result of HIV status.
- **Social withdrawal:** PLHA withdrawing from social and intimate contact.
- **Overcompensation:** PLHA believing that they have to contribute more than other people, or feeling indebted if people are kind to them.
- **Fear of disclosure:** PLHA being unwilling to disclose their HIV status because they are afraid of the consequences.
2.2 How does stigma develop?

Stigma is a complicated process which builds up over time. It moves between personal and group perceptions, where each feeds off the other.

Here is an example of how the process may occur:

People may point out a difference and label it – for example: he coughs a lot, so he must be ill.

Then they may say that the difference is due to negative behaviour – his sickness is caused by his sinful and promiscuous behaviour.

Then they separate ‘us’ from ‘them’ – we are not like them, we are not sinful but they are.

Then there may be a loss of status as well as discrimination – they don’t deserve respect, we should not mix with them, we can treat them in a particular kind of way.

2.3 Why does stigma develop?

HIV/AIDS has been stigmatised because:

- It can be fatal and therefore causes fear – there is still much misinformation on how HIV is transmitted.
- People living with HIV may be a drain on poor families.

These 2 reasons are examples of what is called instrumental stigma – stigma based on resource concerns and ignorance of risk.

- It is often associated with behaviour which is already stigmatised, such as ‘promiscuity’.
- It is seen to be avoidable, i.e. to result from ‘irresponsible’ behaviour or ‘choices’.

These 2 reasons are examples of what is called symbolic stigma – stigma based on moral judgements.

Stigma serves various psychological and social functions:

- As a form of defence (against fear and vulnerability): The fear associated with HIV/AIDS enables us to distance ourselves from those seen to be ‘dangerous’ or ‘infectious’ and allows us to falsely deny our own risk of infection, as a form of self-protection or community protection.
- A form of control: By excluding people who are seen as morally undesirable stigma controls behaviour.
- Blame: By labelling people who have allegedly ‘chosen’ to be ‘irresponsible’, stigma allows society to punish those who it believes could have avoided HIV infection.
- Dealing with differences (non-conformity): Stigma helps people who judge or are threatened by those who are different to them to justify their beliefs – e.g. attitudes to gay people, sex workers, independent women, etc.
- A form of power: Stigma helps people to have power over PLHA and keep resources for themselves.
2.4 What impact does stigma have?

Stigma has a powerful impact on individuals, communities and society:

- It results in a range of excluding behaviours towards people thought to be HIV-positive.
- It isolates, divides and breaks down communities.
- It undermines equal human rights.
- It results in the internalisation of blame and shame, which in turn makes it more difficult to fight against stigma.
- It undermines community health by reducing access to HIV prevention, voluntary counselling and testing, treatment, support and welfare benefits for those who are living with HIV. For example, PLHA may be scared to get proper services and treatment because they fear discrimination and rejection. People may be scared to go for an HIV test because they worry that if the test result is positive they will suffer from stigma and discrimination.
- Stigma also allows people to see PLHA as being different and inferior. There is a strong judgmental attitude – where the people who stigmatise judge, and PLHA feel judged. This separates PLHA who are made to feel different. It discourages people from associating with PLHA lest they are also seen as ‘having AIDS’.

There are different responses to HIV and AIDS in communities – they vary from community to community. There are also sub-groups within communities who may hold differing views, for example, in a faith-based organisation, congregants may be judgemental, but the minister may preach acceptance and non-discrimination; different organisations may take different stances on prevention and condom use – and this will influence their perceptions of the causes of the spread of HIV; schools may accept or reject HIV-positive children. The levels of acceptance, of care and support, and of openness and disclosure all influence the levels of stigma and discrimination in a community.

2.5 How does HIV/AIDS stigma relate to other forms of stigma and discrimination?

HIV stigma may be overlaid upon other pre-existing stigmas and prejudices. This is often true for vulnerable groups. The particularly severe HIV stigma faced by the young, the poor and women is partly due to the existence of these multi-layered stigmas. Regardless of HIV, the poor are considered to be of a lower social status and are often marginalised as a consequence. Women also are marginalised and discriminated against relative to men in the family and society. When these characteristics combine they can result in even greater marginalisation and a lower social status – for instance, young, poor women are often seen as least important in families and society.

A further example is the multiple stigmas faced by sex workers, who are stigmatised for being sex workers, women and HIV positive all at the same time.

Age and gender also intersect, such that younger women are more stigmatised and blamed for HIV than older women, because of beliefs that young women – but not old women – lead promiscuous, careless, materialistic lives that result in HIV.

Another example of multiple stigma is HIV stigma in conjunction with the stigma associated with real or perceived infertility. Young, married women with HIV most often face this dual stigma. On the one hand, it is unacceptable for young, married women to either not have children (in which case they are assumed to be infertile and stigmatised for it) or to stop childbearing before having the socially expected number of children (in which case they may be stigmatised for breaking social and gender norms). On the other hand, the community frowns upon women with HIV having children. Thus these young women face multiple, simultaneous stigmas.


2.6 Stigma and gender

Women are more susceptible to HIV for various physical, social and sexual reasons. This is why the fastest growing population infected by HIV/AIDS is women. In addition, women often face the burden of caring for family members who are ill or dying, resulting in additional pressures placed on them. It is often the grandmothers who are left to take care of grandchildren on a small pension, when their children die of AIDS.

Many ideas and expectations regarding male and female behaviour make it acceptable for men to have more than one sexual partner without using protection. Many women are unable or unwilling to challenge this situation. Low social status and economic dependence prevent many women and young people from having control over their own risk of HIV infection. With little negotiating power, women may have no choice other than to barter sex for survival and/or engage in sex without the use of a condom.

As society’s traditional caregivers, women carry the main psychosocial and physical burden of AIDS care. Yet they have the least control over, and access to, the resources they need to cope effectively. Very few men share domestic responsibilities and family care with their partners. This situation is exacerbated when women care for family members and yet care for themselves as well, especially if male partners die first. Because much of the care and support for people affected by HIV/AIDS falls on women’s shoulders, a major task is to find ways of lessening women’s extra workload.

All of this influences stigma in relation to gender, for example:

Perceived risk of HIV infection: Married women are perceived to be low risk as it is presumed they are monogamous; there may therefore be greater stigma when a woman finds out she is HIV positive.

Blame: Women are blamed for HIV/AIDS and bear the brunt of stigma in spite of the fact that poverty forces many women to engage in transactional sex (sex in exchange for money or goods, e.g. food, rent, etc.).

Gender-based power relationships also play a more direct role in the blame women face. Even if the man brings infection to the couple, his power allows him to shift the blame and stigma to his female partner. The structure of gender-based power means that women are more easily blamed and that their transgressions tend to be regarded more severely than men’s.

2.7 Why do we need to do something about HIV/AIDS stigma?

Stigma and the discrimination that results from it cause a lot of problems for PLHA.

Internal stigma: PLHA internalise stigma, they feel that they are to blame, or that they deserve the disease. They may also fear discrimination and rejection. This can add to the other challenges of being HIV positive.

Barriers to safer sex and behaviour change: The fear of their partner’s response is often the cause of not being able to communicate about safer sex and risk, and negotiate condom use. People’s perception that only certain people get HIV (gays, immoral people, black people) can result in them denying their own risk and therefore seeing prevention as applying to others, not themselves.

Barriers to support: PLHA may need support and care – physical, emotional and spiritual. This is often denied for fear of disclosing their status to others. This means that they cannot get support from others and have to deal with the problems of the disease on their own.
Barriers to health care: PLHA may not seek health care and treatment because they fear stigma and discrimination. This manifests itself in many forms – prevention, testing, disclosure, and care and support. For example:

- Delaying seeking treatment for medical problems which could result in unnecessary suffering and/or a deterioration in health.
- Delaying medical monitoring and exploring eligibility of ART for fear of revealing their status.
- Not seeking treatment for TB for fear of being labelled HIV positive even if their status is HIV negative.
- Barriers to voluntary counselling and testing (VCT): This affects community VCT campaigns where people are encouraged to ‘know their status’. People fear the stigma and discrimination should the result be positive.
- Women who are living with HIV may not get onto treatment to prevent mother-to-child transmission because they are afraid of stigma and discrimination. This is also true for preventing transmission through breast-feeding.
- Attitudes of health care staff are a further barrier to health care. The health-care provider may pass the PLHA to another provider because they do not want to treat the PLHA. Sometimes PLHA will not get proper care because the health-care worker believes that the situation is hopeless and that nothing can be done for those living with HIV.

2.3 Summary

- The main causes of stigma relate to incomplete knowledge, fear of death and disease, sexual norms and a lack of recognition of stigma.
- The link between HIV and sexual transmission introduces layers of moral judgements where people with HIV are stigmatised for their perceived immoral behaviour.
- Stigma is rooted in attitudes and behaviour – people often do not recognise that their words or actions are stigmatising.
- Socio-economic status, age and gender all influence the experience of stigma. The poor are blamed less for their infection than the rich, yet they face greater stigma because they have fewer resources to hide an HIV-positive status. Youth are often blamed for spreading HIV through what is perceived as highly risky sexual behaviour. While both men and women are stigmatised for breaking sexual norms, gender-based power results in women being blamed more easily. At the same time, the consequences of HIV infection, disclosure, stigma and the burden of care are higher for women than for men.
- Those associated with people with HIV and AIDS, especially family members, friends and caregivers, face many of these same experiences in the form of secondary stigma.
- PLHA and their families develop various strategies to cope with stigma. Decisions regarding disclosure depend on whether or not disclosing would help to cope (through care) or make the situation worse (through added stigma). Some cope by participating in networks of people with HIV and actively working in the field of HIV or by confronting stigma in their communities. Others look for alternative explanations for HIV besides sexual transmission and seek comfort, often turning to religion or traditional healing to do so.
- Stigma impedes various programmatic efforts. Testing, disclosure, prevention and care and support for people with HIV are advocated, but are challenged by stigma. Testing and disclosure are recognised as difficult because of stigma, and prevention is hampered because preventive methods such as condom use or discussing safe sex are considered indications of HIV infection or immoral behaviours and are thus stigmatised. Available care and support are accompanied by judgemental attitudes and isolating behaviour, which can result in people with HIV delaying care until it is absolutely necessary.
- There are also many positive aspects to the way that people deal with HIV and stigma. People express good intentions to not stigmatise those with HIV. Many recognize that their limited knowledge has a role in perpetuating stigma and are keen to learn more. Families, religious organisations and communities provide care, empathy and support for PLHA. Finally, people with HIV themselves overcome the stigma they face to challenge stigmatising social norms.
## Section 3

### 3. Intervention options

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### Introduction

Dealing with stigma needs to take place on various levels – the personal level (information and education, self-awareness and consciousness-raising); the community and civil society (community outreach, awareness campaigns and education); and the institutional level (e.g. faith-based organisations, the media, workplace, schools, educational and health institutions). These efforts need to be supported by programmes, policies, guidelines and legal frameworks on both national and international levels. In this section we describe a range of interventions to deal with stigma. We begin by outlining the importance of a national strategy which is necessary to support stigma mitigation work. This is followed by an overview of the rights, laws and policies we can use to reduce stigma. Concrete action is also important, and a range of activities are described in this respect: outreach, targeting influential institutions and human rights literacy are all explored. These can be supported by interventions such as the provision of credible information, running workshops and counselling. The section concludes with an outline of a framework to measure our work regarding stigma.

### Who should play a role?

Tackling HIV/AIDS stigma is everyone’s responsibility and a concerted effort from all role players and stakeholders in society is essential. The following is a guideline for who could be involved:

- All individuals and groups have a role in reducing stigma.
- Families caring for PLHA can adopt a more positive attitude.
- NGOs and other community-based organisations can train their own staff to recognise and deal with stigma, incorporate ways to reduce stigma in all activities, and critically examine their communication methods and materials.
- Religious and faith-based organisations can be supportive of people living with HIV and AIDS in their role as religious leaders and can incorporate ways to reduce stigma in their community service activities.
- Health care institutions can train both new and experienced providers on stigma, while at the same time, risks faced by providers need to be acknowledged and minimised.
- Media professionals can examine and modify their language to be non-stigmatising, provide accurate, up-to-date information on HIV, and limit misperceptions and incorrect information about HIV and people living with HIV and AIDS.
- Workplaces can develop and implement good policies on stigma and discrimination.
- Civil society organisations, social movements, cultural movements, traditional leaders, traditional healers and others all play a role in shaping attitudes and behaviour and also role-model attitudes to HIV/AIDS and to PLHA.

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**Need to know more?**

Additional information on the interventions discussed in this section is provided in Section 7. Tools to support interventions are provided in Section 4.
**Interventions**

### 3.1 A national strategy

Ideally, stigma mitigation work should be linked to a national strategy on HIV/AIDS stigma. A national strategy brings together all the key elements involved in tackling stigma, and translates this into action.

Any national stigma strategy should honour seven key principles:

- Strategies should be based on evidence.
- Strategies should be multi-level, multi-sectoral and holistic.
- Strategies should use a gender lens.
- Strategies should use a rights approach.
- Strategies should be sustainable.
- Strategies should be mainstreamed.
- Strategies should involve PLHA.

A national stigma strategy should:

- provide an appropriate legislative and policy framework
- lobby pro-actively for all social forums to identify and address stigma explicitly
- advocate for the reduction of AIDS stigma in all public forums, including the popular media
- address the role of education, health and faith sectors
- address the role of social and cultural movements, and civil society in general
- explore workplace interventions
- attach an anti-stigma component to all levels of organisational and community planning
- provide consistent, coherent, accurate and legitimate information about HIV and AIDS
- promote experiential workshop processes for values clarification
- support counselling and support group initiatives
- hear the voices of PLHA and PLHA organisations
- explore the impact of poverty on stigma
- conduct research, monitoring and evaluation.

Individuals and organisations can implement some of these interventions but there does need to be a process, preferably driven by national government, which takes an integrated and systemic approach to stigma mitigation. All programmes should:

- set clear objectives for desired outcomes and change
- focus a programme on specific needs and priorities in any given situation
- include careful measurement and documentation in programming plans
- ensure that programmes complement the work done by others
- help to foster a comprehensive response
- make people aware of stigma and discrimination
- educate about all aspects of HIV and HIV transmission
- provide safe spaces to talk about values and beliefs about sex, morality and death
- find a common language to talk about stigma.

The work done by the Siyam’kela Project will contribute to a national strategy on stigma related to HIV and AIDS currently being developed by the Chief Directorate: HIV and AIDS and TB, National Department of Health.
There are three interrelated approaches here:

- **Protecting rights:** using a rights-based approach to challenge the government in court to make these rights come alive
- **Enforcing laws:** using existing laws (or promoting the development of new ones) to challenge discrimination, and
- **Implementing policies:** trying to implement policies which promote non-discrimination.

A rights-based approach to stigma and discrimination means locating the needs of PLHA in a human rights context, so that rights can be claimed, asserted and measured. It is a movement away from policy, which is usually at the discretion of government or other policy-makers, towards mechanisms whereby rights can be translated into a concrete form and given status and recognition in international and domestic law. As such, a rights-based approach has the potential to be a powerful and empowering tool.

In this section there is an emphasis on a rights-based approach but where relevant, appropriate policies and guidelines are mentioned. There are limitations to relying on policies and guidelines alone as implementation can become caught in the web of bureaucracy and delayed due to competing priorities, lack of capacity and a shortage of resources. These shortcomings are largely addressed by the rights-based approach which creates a legal obligation on the government.

Nevertheless, good policies may create a framework for greater awareness of stigma and discrimination and an opportunity to challenge discrimination, especially in workplace settings.

The promotion and protection of human rights reduces vulnerability by addressing its root causes, reducing the adverse impact on those already vulnerable, and empowering individuals and communities to respond to the important issues affecting PLHA. The starting point for a rights-based approach is to identify the basic rights of PLHA and the causes of stigma. This is followed by identifying accompanying responsibilities – the duty-bearers need to respect, protect, facilitate or fulfil these needs.

The effects of the abuse of human rights in HIV/AIDS are far-reaching, and include:

- **Increased vulnerability** – certain groups are in greater danger of contracting HIV, as they are already vulnerable and unable to realise their civil, political, and economic, social and cultural rights. This may include, for example, people living in poverty, women, prisoners, and lesbians and gay men. Vulnerable groups are frequently also denied the rights to freedom of association and access to information, and therefore may be prevented from discussing issues related to HIV/AIDS, participating in AIDS service organisations and self-help groups, and taking other preventive measures to protect themselves from HIV infection. Women, and particularly young women, are more vulnerable to infection if they lack access to information, education and services necessary to ensure sexual and reproductive health and prevention of infection. People living in poverty often have poor access to health care, and will be less able to access HIV care and treatment, including anti-retroviral drugs and other medications for opportunistic infections.

- **Stigma and discrimination** – the rights of PLHA are often violated because of their presumed or known HIV status, causing them to suffer both the burden of the disease and the consequential loss of other rights. Stigmatisation and discrimination may obstruct their access to insurance, credit, employment, housing, health care and social services. The result is that those people most in need of information, education, counselling, testing and treatment will not necessarily benefit, even where such services are available. Thus, while there may be formal equality (i.e. everyone is governed by the Bill of Rights and has the protection and access to the rights contained therein) there is a serious question about whether people living with HIV/AIDS are able to claim their rights.

- **An effective response is impeded** – effective HIV prevention, treatment, support and care strategies are hampered in an environment where human rights are not respected. Discrimination against PLHA undermines society’s efforts to prevent HIV infection and to limit the impact of the HIV/AIDS epidemic on our society. Basic rights such as the right to privacy and confidentiality will feed into the success or failure of broader interventions.
3. Intervention options

Over the years, the assembly of heads of state or government of the Organisation of African Unity (OAU) – now known as the African Union (AU) – also adopted a number of resolutions relevant for HIV/AIDS and human rights, including:

- the Tunis Declaration on AIDS and the Child in Africa, which in paragraph 2(1) declares a commitment to “elaborate a national policy framework to guide and support appropriate responses to the needs of affected children covering social, legal, ethical, medical and human rights issues”

- the Abuja Declaration on HIV/AIDS, Tuberculosis and other Related Infectious Diseases, and the Abuja Framework for Action for the Fight against HIV/AIDS, Tuberculosis and Other Related Infectious Diseases. In the Declaration, the heads of state acknowledged that “stigma, silence, denial and discrimination against people living with HIV/AIDS increase the impact of the epidemic and constitute a major barrier to an effective response to it” (Paragraph 12).

Since the Universal Declaration on Human Rights (UDHR), the United Nations has developed a number of international resolutions, guidelines and agreements dealing with human rights. Some of these focus specifically on HIV and AIDS, whilst others provide a framework from which we can draw in relation to rights as they apply to HIV and AIDS (e.g. the Convention on the Rights of the Child (CRC) and the Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW)).

Examples of international agreements which focus on HIV and AIDS specifically include:


- Declaration of Commitment on HIV/AIDS – an important resolution adopted by the United Nations in the UN General Assembly Special Session (UNGASS)

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Examples of international agreements which focus on HIV and AIDS specifically include:


- Declaration of Commitment on HIV/AIDS – an important resolution adopted by the United Nations in the UN General Assembly Special Session (UNGASS)
The South African government's response to HIV/AIDS and human rights

The first public HIV/AIDS policy response in South Africa was in 1992, when the National AIDS Coordinating Committee of South Africa (NACOSA) was formed. The NACOSA policy proved ineffectual to counter the HIV/AIDS epidemic in South Africa, mainly because it was never implemented, and it was replaced by the HIV/AIDS/STD Strategic Plan for South Africa, 2000-2005. In April 2002, the Cabinet renewed its commitment to the Strategic Plan with its four focus areas:

- prevention
- treatment, care and support
- research, monitoring and surveillance, and
- legal and human rights.

Some important guiding principles in the Strategic Plan which impact on human rights include:

- PLHA, their partners, families and friends shall not suffer from any form of discrimination
- the vulnerable position of women in society shall be addressed to ensure that they do not suffer discrimination or remain unable to take effective measures to prevent infection, and
- confidentiality and informed consent with regard to HIV testing and test results shall be protected.

In July 2002 the government established the Joint Health and Treasury Task Team (JHTTT) in order to investigate issues regarding the financing of an enhanced response to HIV and AIDS, based on the Strategic Plan. The JHTTT focused particularly on the treatment, care and support component of the Strategic Plan, and submitted its report to the government in 2003. Following discussions on the report, the Cabinet instructed the Department of Health to develop a detailed operational plan for implementing an anti-retroviral treatment (ART) programme in South Africa. This operational plan was submitted to Cabinet in September 2003 and accepted two months later.

By September 2004 a number of medical centres had started with the roll-out of ART. It is envisaged that there will be at least one ART service point in all 56 health districts across the country and, within five years, one service point in every local municipality.

The Bill of Rights and people living with HIV or AIDS

The South African Constitution has a Bill of Rights. This outlines the basic rights which apply to all South Africans. The most important aspect of this is the right to equality – known as the equality clause. In addition to the right to equality, the following are also important for PLHA:

- **human dignity** – a person or institution (such as a hospital or company) may not insult or damage any person’s self-respect by their words or actions
- **freedom and security of the person** – a person has the right to take their own decisions about medical treatment and pregnancy, e.g. a woman cannot be forced to test for HIV or to terminate a pregnancy because she is HIV positive
- **privacy** – a PLHA has the right to keep his/her status private. An employer or hospital cannot force a person to disclose his/her HIV status or force a person to have an HIV test
- **freedom of expression** – this right is important, especially as a way to ensure that proper information on HIV/AIDS is available to people, for example how it is transmitted, so that they are in a better position to protect themselves from infection. It is very important for schools and educational institutions to make this information available
- **freedom of association** – a PLHA can join any organisation he/she chooses to, and cannot be dismissed because of his/her status. PLHA cannot be forcefully separated from other people
- **freedom of movement and residence** – even if a person has HIV or AIDS, he/she is still free to move around the country. He/she cannot be forced to live in a separate place from others in the community
- **freedom of trade, occupation and profession** – PLHA can choose what kind of work they want to do
- **labour relations** – no person may be unfairly discriminated against at work
- **environment** – this right is particularly important for PLHA who are living in state institutions such as prisons or psychiatric hospitals. It states that everyone has a right to an environment that is not harmful to their health or well-being
- **housing** – PLHA may not be refused a subsidy or loan to buy a house. Evicting a person from a house or flat because of their health is also unlawful
- **health care, food, water and social security** – no person may be refused emergency medical treatment. Hospitals or health care workers cannot refuse to treat a PLHA. PLHA have the right to disability grants if they are too ill to support themselves or their families
- **education** – all people have the same right to a basic education. A school cannot refuse to educate or refuse to admit a PLHA
- **access to information** – everyone has a right to information that is being held by another person and that is needed to carry out or protect his/her rights. If a person feels he/she is being discriminated against because of a certain policy, he/she can demand to see that policy and then challenge it in court. The same right exists with private institutions
- **just administrative action** – if a person feels he/she is being refused a social service for unjust administrative reasons, he/she can demand these reasons in writing
- **arrested, detained and accused persons** – prisoners cannot be treated in a discriminatory or undignified way just because of their HIV status. They cannot be kept separately from other prisoners, and they have a right to privacy about their status.\(^7\)

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The Bill of Rights enshrines the right to privacy and the right to human dignity. These rights mean that an individual is entitled to have his/her HIV status kept confidential; in other words, HIV/AIDS status is private and should not be disclosed to others without consent. While this is an important principle, there are no laws that stop a third party such as a neighbour or friend from disclosing a person’s status. While in theory it is possible to bring a legal action against a third party for breach of confidentiality the costs involved would be prohibitive, and the result would most probably not be worth the effort, time and money involved in the application.

There are, however, certain relationships where confidentiality is protected by law, such as between a doctor and patient, an attorney and his/her client, and an employer and employee. In these instances there are policies or laws in place, or the courts have clarified the position of the parties. In general, if these professionals violate confidentiality, the matter can be taken to the professional bodies or a civil case can be launched. In certain cases, a criminal case can also be launched.

There are various ethical guidelines and legal guidelines which stipulate that doctors, nurses, psychologists and other health care professionals must keep all patient information, including HIV/AIDS status, confidential. This means that, generally, a health care professional cannot disclose the status of a patient without first obtaining his/her consent to do so. While not legally binding, in that they generally cannot be enforced in a court of law, the guidelines are still important because the actions of the professional are held up to scrutiny based on the requirements of the guidelines, judged most often by their own peers in a professional body. In addition there are guidelines which outline disclosure of a patient’s status to another health worker, to a third party (including family members), and to the PHLA’s sexual partner.

Informed consent

Section 12(2) of the Constitution states that people have the right to bodily and psychological integrity, which means that a person must be free to consent to all medical treatment, and has the right to refuse medical treatment.

Consent involves both information and permission. A person must be provided with all relevant information before he/she is examined, treated, tested, given medicine or operated on. He/she must provide his/her express permission to undergo the treatment or test either orally or in writing.

People have the right to refuse medical treatment and testing. They should not be forced or tricked to consent or treatment.

In terms of HIV testing, the HPCSA ethical guidelines say health care workers should not do an HIV test without obtaining informed consent from a person (see the right to confidentiality and privacy). This principle is also reinforced in the National Policy on Testing for HIV of the Department of Health, published in 2000. Thus a person must know what the test is, why it is being done and what the result will mean. A person cannot be coerced or tricked into going for a test. The same is true for HIV vaccine trials, and will also hold true for ART.
3. Intervention options

Access to health care

Health care is a very important issue for PLHA, especially since many are unable to pay for medical insurance or treatment, and so they rely on government services. Section 27(1)(a) of the Constitution states that everyone has the right of access to health care services, including reproductive health care. ‘Access’ to health care means that government must try to provide health care to people who cannot afford it. This is subject to available resources. In addition, no one may be refused emergency medical treatment.

While the Department of Health has put in place laws and policies to guide health care workers in clinics and hospitals on how to deal with PLHA, PLHA often feel discriminated against and victimised when visiting health care institutions. Work still needs to be done on quality of care, access and attitude change in relation to HIV and AIDS services in South Africa.

There are several charters and policies which strive to improve public services. These include:

- Batho Pele, which focuses on eight principles which apply to all public employees rendering services to the public.

Want to know more?
For a summary of the Batho Pele principles see Section 7: Additional information 7.4 The Batho Pele white paper

- the National Patient’s Rights Charter, launched by the Department of Health in 1999, which lists the rights and duties of all people who use government health services. It is not a binding law, but provides guidelines that health care workers and patients are supposed to follow. The Charter says that all health care workers must treat patients with respect, dignity, courtesy, patience and tolerance.

- the HIV/AIDS Policy Guidelines, issued by the Department of Health in October 2000, are being used in government hospitals to treat people with HIV/AIDS. It is not acceptable for a health care worker to treat a patient differently, or refuse to treat a patient, due to his/her HIV/AIDS status. The health care worker cannot refuse to clean or feed a patient because of fear of infection. This is also reaffirmed in the HPCSA Guidelines.

Rights of women

Women have a right to equality under the Bill of Rights of the Constitution, which states that discrimination on the basis of sex, gender and pregnancy is not allowed. In reality, however, many women find it impossible to ‘make this right real’. This is due to factors such as economic dependence, tradition and customary practices.

Since 1994, the South African government has put in place several laws and policies that focus on giving women an equal position in society.

Some of the important laws and policies that affect women, especially related to HIV/AIDS, include the following:

- Section 12(2) of the Constitution gives everyone the right to bodily and psychological integrity, which includes the right to make decisions about reproduction.

- One law that has been put in place to make this right real is the Choice on Termination of Pregnancy Act (No. 92 of 1996), as amended, which allows for a woman to terminate a pregnancy and lays out the conditions for this to occur.

Want to know more?
See Section 7 Additional Information: 7.5 TOP - key point summary.

- Prevention of mother-to-child transmission of HIV (PMTCT): the Department of Health has a policy of providing the anti-retroviral drug Nevirapine to pregnant women to prevent mother-to-child-transmission of HIV. The provision of the drug reduces the risk of the transmission of HIV from mother to the child. A woman must give informed consent for herself and the baby before being given Nevirapine. She can refuse to be tested and to take the drug. There are various reasons why a woman may refuse treatment, and while these should be explored through counselling, it is important to respect her decision as to whether or not to take the drug. Often it is only a matter of providing the correct information about the effects and the impact of Nevirapine that will help a woman make a decision about it. The husband or father of the baby does not need to consent or even be told of the decision that a woman makes with respect to the drug.
- Sterilisation: A woman with HIV/AIDS cannot be forced to undergo a sterilisation. She can only be sterilised if she gives informed consent, based on all the information. As sterilisation is considered a surgical procedure, a girl under the age of 18 years must have the consent of her parents or legal guardian before the procedure can be undertaken.

- Rape, sexual violence and abuse: South Africa has one of the highest rape rates in the world. When violence is involved, it often results in vaginal tearing, which increases the chances of HIV transmission. If a woman has been raped, it is a very good idea for her to undergo an HIV test, especially if she was HIV negative before the rape. Being tested within 72 hours of the rape is very important because the woman can then obtain access to a combination of ART that can reduce the chances of HIV transmission. While this is a difficult time in the life of the rape survivor and the police and health care workers may think they are working in the best interests of the woman, the requirements of informed consent, pre- and post-test counselling still exist and are very important for both the test and the administration of the ART. In 1997, the law was changed to create stricter penalties for rapists with HIV/AIDS. Under the law, if a person accused of rape knew he was HIV positive at the time of the rape, he is automatically denied bail. If a person convicted of rape knew that he had HIV at the time of the rape, he will receive a minimum sentence of life imprisonment, even if the rape does not result in HIV transmission. There is a proposal to change the law to require that those charged with rape be tested for HIV, even without their permission. This is still under consideration and has not yet been passed. In addition, there is a proposal to change the definition of rape to make it broader and to make it include a situation whereby a person who knows he/she has HIV/AIDS and has unprotected sexual intercourse with his/her partner, even with consent, without first telling his/her partner of his/her status, may be found guilty of rape.

- The Domestic Violence Act (No. 116 of 1998) defines domestic violence broadly and also makes marital rape a crime. Women who are in violent relationships are not usually able to negotiate safer sex with their abusers and this puts them at an increased risk of HIV/AIDS. While many men and women argue that this is a tradition that needs to be protected, it is unlikely that a woman in this situation is able to negotiate safer sex with her husband, and thus she is more susceptible to HIV/AIDS. Some rights are provided for such women mainly with respect to inheritance in the Recognition of Customary Marriages Act (No. 120 of 1998).8

- Virginity testing: This is controversial and is seen by some as being discriminatory, and increasing women’s vulnerability to HIV transmission and stigma. While there are those who argue that virginity testing actually encourages young girls not to have sex, and is a way of preventing the spread of HIV, others see it as a practice that violates the girls’ right to privacy and dignity. In addition, it stigmatises those girls in the community who are not virgins, making them more susceptible to abuse and rape. The Children’s Bill currently at Parliament for review proposed to outlaw virginity testing and has been met with resistance from various communities.

- Another cultural practice that impacts on the spread of HIV/AIDS is polygamy, the right of a man to have more than one wife. While many men and women argue that this is a tradition that needs to be protected, it is unlikely that a woman in this situation is able to negotiate safer sex with her husband, and thus she is more susceptible to HIV/AIDS. Some rights are provided for such women mainly with respect to inheritance in the Recognition of Customary Marriages Act (No. 120 of 1998).8

3. Intervention options

Rights of children

Children can be affected by HIV/AIDS in several ways. They can live with HIV/AIDS, or deal with the illness or death of their parents or those around them, such as friends, teachers and other family members. It is important within this context to ensure that children can live as normal a life as possible, allowing for their fullest social, physical, emotional and spiritual development.

Children who are infected or affected by HIV/AIDS face many forms of discrimination and human rights abuses. These may include:

- being tested for HIV without their consent, or the consent of their parent or guardian
- being denied access to schools due to their known or presumed HIV status, or being subjected to verbal and physical abuse in schools
- being denied access to adequate sexual and reproductive health information, and
- being left to care for younger siblings and struggling without any income to support the family, which may result in an increased chance of engaging in risky sexual behaviour in order to get money (sex for money, food or goods) or subject to abuse (for instance, if a child is out late because he/she is working to make money, he/she is more likely to be exposed to abuse on his/her way home).

Children are a special segment of society because often they cannot take care of themselves and they need special attention and protection. While children are included in all of the rights in the Bill of Rights, section 28 of the Constitution recognises the need for special protection and outlines the rights of children.

These rights include:

- the right to family care or parental care
- the right to basic health services
- the right to basic social services
- the right to be protected from abuse or bad treatment, and
- the right to be protected from child labour.

There is no requirement for progressive realisation of these rights. This means that their rights are to be made available immediately.

The Constitution and laws in place that deal with children all stress the importance of determining the ‘best interests of the child’. The ‘best interests of the child’ often requires an examination of various factors, and weighing up of different rights. There are various important laws and policies that impact on children who are infected or affected by HIV/AIDS, including the Child Care Act (No. 74 of 1983) which provides children with protection from exploitation and abuse, and identifies situations whereby children are ‘in need of care’, and the South African Schools Act (No. 84 of 1996) makes education compulsory for children under the age of 15 years – this would also include HIV-positive children.

Health care rights for children include:

- Children under the age of 6 years have a right to free medical care in government clinics and hospitals.
- In terms of HIV testing, a child of 14 years or older can give informed consent for a test, and is also entitled to the same confidentiality as any adult. This means that a health care worker cannot disclose his/her status to anyone, including his/her parents, without his/her consent. When a child is younger than 14 years, a parent or guardian must provide consent for an HIV test. The results are to be provided to the parent or guardian, and they can decide to disclose to the child, depending on the child’s age and whether it is in the child’s best interests to know the results.
- In terms of contraception, a child that is younger than 14 years can ask for condoms from a local clinic. However, a girl must be 14 years or older to access oral contraceptives (‘the Pill’) as this is considered to be ‘medical treatment’ (see previous section on informed consent). A girl of any age can consent to a termination of pregnancy, without the consent or knowledge of her parents or guardian.
- Since children can consent to medical treatment if they are 14 years or older, this will undoubtedly impact on their access to ART. Presumably, they would be able to give informed consent to the treatment without the knowledge or consent of their parents/guardians.\textsuperscript{10}

\textsuperscript{9} There is a Children’s Rights Bill which is being reviewed by Parliament currently. This Bill would replace various sections of the Child Care Act.

Accessing social assistance

Section 27(1)(c) of the Bill of Rights in the Constitution makes it clear that the government, subject to the resources it has available, has to make sure that everyone has access to social security, including social assistance for those who are unable to support themselves.

When people are too sick, too young or too old, or injured, the Social Assistance Act (No. 9 of 1992) provides the framework for how people can access government assistance.

The Department of Welfare’s Ten point plan for action (Jan 2000) noted that:

- HIV and AIDS are disabling conditions.
- People living with HIV and AIDS will qualify for social security and assistance where necessary, which includes nutrition, transport, rent, burial costs and books.
- Staff in the Department need to be educated about the need for confidentiality.

There are various types of grants available, such as foster care grants, old age pensions and child support grants. People with HIV become eligible for the disability grant when they have a CD4 count less than 200 and/or when they are symptomatic.

Dealing with rights violations

This section will outline various actions that can be taken if people believe that their rights have been violated and where people can turn to for assistance. It will also describe the various organisations that can be approached for assistance and the difference between civil and criminal charges. The gathering of information is an important part of the process. Ways to do this include interviewing, taking a statement, making a sworn affidavit and collecting evidence.

Enforcing existing laws

Like every citizen of South Africa, PLHA are protected by all laws. However, there are very few laws which are specifically HIV/AIDS focussed. Exceptions are the Labour Relations Act and the Employment Equity Act, which together prevent pre-employment HIV testing or unfair dismissal on the grounds of HIV status. So if someone believes that they were not employed because they are HIV positive or that they were dismissed from their employment on the basis of their HIV status, then they can go to court to challenge this discrimination.

The Promotion of Equality and Prevention of Unfair Discrimination Act (No. 4 of 2000) lists grounds for non-discrimination. While it does not specifically mention HIV/AIDS as a ground for non-discrimination it does say that:

“... any other ground where discrimination on that other ground –

- causes or perpetuates systemic disadvantage;
- undermines human dignity; or
- adversely affects the equal enjoyment of a person’s rights and freedoms in a serious manner that is comparable to discrimination on a ground listed in paragraph (a).”

In other words if a person feels they have been discriminated against because of HIV/AIDS they could use the act to bring a court action. HIV/AIDS will probably be considered for inclusion in the Act in the future (see subsections 34(1) and (2) of the Act).

And finally, Section 9 of the Constitution, the Equality Clause, lists 17 grounds for non-discrimination: race, gender, sex, pregnancy, marital status, ethnic or social origin, colour, sexual orientation, age, disability, religion, conscience, belief, culture, language and birth. While HIV/AIDS is not included in this definition, it has been ‘read in’ to (i.e. included in) the definition of disability.
There are various institutions that are in place to deal with human rights violations. Some of these are discussed below:

**South African Human Rights Commission (SAHRC)**

The South African Human Rights Commission (SAHRC) was established by the Constitution, and is governed by the Human Rights Commission Act (No. 54 of 1994). The SAHRC’s mandate is to promote, protect and monitor human rights in South Africa.

The SAHRC deals with cases of alleged human rights violations free of charge. A person can complain to the SAHRC if he/she believes that his/her rights have been abused or violated. The Commission does not take on all cases, however.

**The Equality Courts**

The Equality Courts are established by the The Promotion of Equality and Prevention of Unfair Discrimination Act, 2000 (Act 4 of 2000). There are equality courts in all nine provinces.

The Courts seek to achieve the quick and informal processing of cases, which enables participation by the parties to the proceedings, and also seeks to ensure access to justice to all people. Cases can run concurrently (at the same time) as criminal cases.

The Act allows for cases to be brought before the equality courts that relate to harm suffered due to unfair discrimination, hate speech and/or harassment.
Complaints against medical doctors

There are several relevant organisations with regards complaints against health professionals:
- South African Medical Association (SAMA)
- Health Professions Council of South Africa (HPCSA)
- South African Nursing Council (SANC).

Civil claims

A civil claim is a claim for money for compensation for damages (harm) that was done. Civil claims can be launched in the following cases:

- where one’s right to confidentiality has been violated, it is possible to launch a civil claim for damages against the health care worker or the hospital/clinic that violated the right to confidentiality
- if one has been assaulted, it is possible to claim damages for pain and suffering, loss of wages and medical costs from the person who assaulted one. A criminal charge can also be laid against that person (see below)
- if someone violates one’s right to privacy and dignity, then a claim can be launched against that person
- if someone says something harmful about one in public, then one can claim damages against the person for the harm caused by the statement(s), and
- a civil claim for pain and suffering is possible when a person has done something that causes one shock, body disfigurement or paralysis, damages one’s health or personality, or cuts short the number of years one is likely to live (e.g. though a serious car accident).

Non-governmental organisations, community-based organisations and paralegals

These provide information on rights and services to assist with rights violations.

Want to know more about any of these organisations, including contact details?
See Section 7 Additional information:
7.8  Dealing with human rights violations – organisations and resources.

Want to know more about lodging a complaint against a health professional?
See Section 7 Additional information:
7.8  Dealing with human rights violations – organisations and resources.

Want to know more about civil claims?
See Section 7 Additional information:
7.8  Dealing with human rights violations – organisations and resources.
Intervention options

3. Intervention options

Criminal charges

A person commits a crime if he/she breaks the law. If a crime is committed against a person, he/she can make a criminal case against the person who committed the crime, or the state (the police) can bring a charge against that person. The police can investigate and bring a charge and then the attorneys employed by the government should prosecute the case, if there is enough evidence to do so. For example, criminal charges can be brought in cases where:

- a health care worker takes blood from a patient without his/her consent.

- someone seriously harms another person’s dignity and standing in the community, by, for example spreading malicious gossip about him/her. Then the person causing the harm can be charged with a crime called ‘crimen injuria’.

It is important to remember that although a person can lay a charge, it may not be a good idea for him/her to do so. Deciding whether to lay a charge requires balancing the negatives and positives of the situation. For example, the complainant (the person laying the charge) will have to reveal his/her status, it will take time for the case to be investigated and for the case to go to court and be concluded, and the outcome may not be in his/her favour. On the other hand, it may be an important principle to uphold, despite the outcome, and the complainant may want to ensure that the person who caused the harm does not do the same to other people. The complainant must decide whether to pursue the case.

The police will not charge someone for a crime lightly and will carry out their own evaluation, looking at a number of factors such as the seriousness of the incident, the importance of deterrence (making sure that others do not do the same thing), and the likelihood of conviction. However, remember that even if the police do not lay charges, it does not mean that the incident did not happen and was not important; rather it means that they decided not to go forward with laying charges for various reasons.
### 3.3 Reaching out to communities

In this section we explore why community partnerships are an essential component of any HIV and AIDS initiative, including work on stigma. Some practical, hands-on community outreach activities are discussed.

**Here are some reasons why communities are so important in HIV and AIDS work.**

**Communities:**
- understand local needs and can ensure programmes are responsive the particular needs of their community
- represent and provide a voice for marginalised groups
- provide leadership and role models with whom people identify
- can take important messages about HIV and AIDS, and translate these messages into a language which local people understand
- are the home for key organisations in HIV and AIDS work: non-governmental organisations and AIDS service organisations, faith-based organisations, and self-help groups
- are the base from which key role-players in HIV and AIDS work operate: activists, volunteers, trade union members, employers and employees, etc.
- community mobilisation underpins the success of any public health campaign: this is particularly so with HIV prevention work, and in this case anti-stigma work
- most importantly, communities are where people living with HIV and AIDS and those affected by this live. This ensues PLHA participate in, inform, guide, support and receive the services and programmes directed at them.
- the people running the programmes remain open to new ideas and adapt to the changing needs of those served by the project
- the people involved do not think about health just in terms of the prevention and treatment of the disease. Rather, they think of each person’s social, emotional and physical situation.

Any work dealing with HIV and AIDS stigma needs to be rooted in the community. Community outreach is a way of ‘reaching out’ and educating people in a community about HIV and AIDS, the stigma linked to it and the effects of this stigma. Community outreach can also address stigma by challenging attitudes and promoting acceptance of PLHA. This kind of outreach is usually done in places where people live and work, by people and organisations from the community. These people and organisations are important role models for tolerance and openness.

**Successful community-based programmes have some common features:**
- they begin small and grow slowly, as the needs and resources of the community grow and change
- they involve the community in each part of the work, from planning to evaluation
- they ask people from the community to take part in the work
- they use leaders whose main interest is serving the community, not advancing their careers or making money
- the people running the programmes remain open to new ideas and adapt to the changing needs of those served by the project
- the people involved do not think about health just in terms of the prevention and treatment of the disease. Rather, they think of each person’s social, emotional and physical situation.

This section on community outreach is at the heart of the other activities described in this section. Advocacy and lobbying, using policy and legal frameworks, the promotion of human rights literacy, running workshops, raising awareness, targeting influential institutions and providing credible information are ways to strengthen community outreach and community mobilisation work.

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14 Adapted from: *HIV, Health and Your Community* by Reuben Granich and Jonathan Mermin.
3. Intervention options

Ideas for community work regarding stigma

- **Giving talks to meetings**

Churches, mosques, temples, schools, hospitals, women’s groups, youth groups, sports groups and unions often have regular meetings of their members. You could approach these groups to give a talk on stigma and discrimination. You should use this opportunity to give good, clear information on HIV and AIDS, on stigma and its impact. If possible, bring in an experiential component where people are asked to get in touch with their own feelings and experiences. This could be enhanced through a PLHA presentation. If you do ask a PLHA to present, make sure that they are willing to disclose and have support if necessary. Remember to try and adapt the talk to the needs and concerns of the target group so they feel that the session is relevant to them. Street children, mothers and truck drivers are all different, and you should start with what they see as the most important issue.

- **Doing outreach work in bars and shebeens**

Bars and shebeens are often places where people meet for sex. Sometimes this will be sex for money with sex workers. While it may be difficult to do work on stigma and attitudes while people are under the influence of alcohol, it is possible to focus on safer sex and condom use. By making safer sex and condoms normal these practices are seen as part of everyone’s life, not just PLHA. You can also focus your efforts on educating the staff about HIV and AIDS and stigma. If they are equipped with this information and positive attitude they are in a position to influence customers. Many people are influenced by their social group or context, and a bar or shebeen is an excellent place for new attitudes to be learned.

If you are going to do work in shebeens and bars, some basic steps are:

- visit the bar or shebeen and get to know the people there – make sure you meet the boss
- learn the rules of behaviour at the bar or shebeen and always pay your bill
- if sex is being exchanged for money, learn how the business works
- learn about the bar or shebeen workers’ private lives: their backgrounds, future plans, relationships, families, sex lives and health conditions
- learn about the workers’ beliefs about HIV and sex
- choose a time and place for HIV education that does not disrupt the day for the workers
- be flexible – don’t push people too hard to change
- show that you do this work because you care about the people working at the bar or shebeen and their clients, and want them to stay healthy.

- **Community meetings**

Community meetings are an excellent way of bringing together a group of people to get across a message of acceptance and tolerance towards PLHA, their family and friends. It would be a good idea to use influential people in the community (such as traditional or elected leaders, ministers, organisers) to call such a meeting to give it legitimacy. It would also be helpful to invite a PLHA who is confident and open about their status to raise issues of stigma and acceptance at such a community meeting. The meeting can simply be an opportunity to raise awareness, it can be the starting point of a stigma campaign, it can elect people to start a lobbying campaign, and so on.
Developing door-to-door campaigns

In some communities volunteers come together to plan and implement door-to-door campaigns during which homes are visited, information is handed out, discussions are held and openness to HIV and AIDS and PLHA is promoted. In South Africa the government’s Khomanani campaign is training and working with volunteers countrywide to do this kind of work. These kinds of personal encounters can be very useful and they allow a kind of intense and challenging dynamic to be set up.

Setting up support groups for people affected by stigma

In many communities there are organisations, such as the National Association of People Living with HIV/AIDS (NAPWA) or the Treatment Action Campaign (TAC), which are already setting up and running support groups for PLHA and their families. Where these organisations do not exist some communities may set them up themselves. These support groups offer safe spaces for PLHA to get support from each other and challenge internal and external stigma.

Reaching out to sex workers

A sex worker is any man or woman who exchanges sex with multiple partners for money, food or housing. In some communities sex work is seen as normal while in other places it is frowned upon. Attitudes to sex workers are closely linked to attitudes to PLHA – they are often both seen as breaking the norms of society. If you are able to reach out to sex workers and assist them to feel part of the community you are contributing to increased community tolerance. In some parts of the world sex workers have formed groups to protect their rights. You can help sex workers in your community organise themselves. At the same time you can pass on valuable information about safer sex. You can also challenge attitudes to sex workers in your community as a part of community tolerance towards difference, including difference based on HIV status. If there is an existing sex worker project in your community then it would be advisable to work with this group as getting access to sex workers can be difficult. Understandably, they often are suspicious of the motives of people who want to help or work with them.

Working with traditional healers

Many South Africans visit traditional healers, even if they use western medicine at the same time. This is also true of PLHA. These healers are very important sources of support and acceptance of PLHA, and can play a role in challenging negative attitudes.

Some ideas for working with traditional healers:

- find out who the traditional healers are in your community
- meet with them and start a discussion on HIV and AIDS and stigma
- tell them about your work in stigma and what causes it
- invite them to be a part of this work
- discuss what messages of care and support would be helpful to address stigma.

Focus groups

Focus groups are a useful way to understanding needs, experiences and perceptions of community groups. A focus group is a small group of people (around 8-12 people) who represent the community or a target/special interest group with whom you plan to work. For example, if you want to create a poster or pamphlet on HIV/AIDS stigma, bring together a focus group and ask them about what messages regarding stigma and acceptance they would like to see. The focus group can help with the words, the pictures and the tone. After you have made the poster, ask another focus group from the community to look at it and give suggestions. Once you know the poster is understandable and works well, you can make copies and distribute it in the community.

Information on running support groups can be obtained from HIVSA at the Chris Hani Baragwanath Hospital (www.hivsa.co.za) in Soweto.
3. Intervention options

- **Community theatre**

  Community theatre is used all over the world to raise awareness, challenge ideas and provide educational entertainment (edutainment) in communities. Theatre attracts people, people relate to it, it does not require literacy, it can be reach out into people’s emotions, it is undemanding and often more enjoyable than a talk. Community members can write about their own stories and get involved in acting, directing and stage management. These stories can include a section where the audience is invited to participate. In this way the theatre reflects real issues which the community is facing. It is useful to have a discussion with the audience and actors after the drama which focuses on the key educational messages.

- **Using local media, including radio**

  Local newspapers and magazines can run stories about PLHA which help people in a community understand the daily reality of the PLHA and promote acceptance. These stories also remind PLHA that they are not alone and that they are visible and recognised. Community radio stations can have interviews with experts and PLHA on various topics to challenge fears and promote acceptance. Papers and radio can have regular PLHA columns to keep HIV and AIDS issues topical and foremost in the minds of the community. Some media campaigns use popular or famous people to get across a message of acceptance. Stories which cause a strong emotional response can be an effective way to move people and make them think about the consequences of their thoughts and actions.

- **Films and videos**

  In some communities there may be opportunities to screen films or videos in community halls, in libraries, in halls linked to faith-based organisations, in clinics and in schools. These films or videos can be chosen for their content linked to HIV/AIDS stigma. This is a powerful way to get across a message of acceptance. Stories which cause a strong emotional response can be an effective way to move people and make them think about the consequences of their thoughts and actions.

- **Funerals and burial societies**

  Burial societies are organised saving schemes to assist people who have experienced the death of a family member. If the members of a burial society are offered the chance to learn about HIV and AIDS, and stigma, then they may be in a position to assist the bereaved to be more open about the cause of death if it was related to AIDS. Similarly, funeral speeches are powerful opportunities to bring HIV and AIDS out into the open – in most cases the cause of death is known to everyone but because of fear, shame and stigma this ‘open secret’ is not discussed. If it is brought out into the open there is often a sense of relief.

- **Schools and school governing bodies**

  Schools in many communities are feeling the effects of HIV and AIDS through learners and teachers who are infected or affected. School governing bodies are made up of influential parents in the community and if they can be persuaded to address stigma then much good work can be done. This stigma work could include making sure that messages of acceptance go out to learners and that teachers who are affected are retained as employees. In addition, schools can be used for community meetings, support group meetings and so on.

- **Cultural events**

  Any event which brings people together is an opportunity to challenge attitudes and actions.
Many organisations are involved in advocacy without even realising it. Advocacy is an important tool to influence leaders and decision-makers. In this section advocacy is explained, and a useful step-by-step framework is provided.

**What is advocacy?**

Advocacy is an organised or planned effort to influence decision/policy-making and programme implementation. The goal of advocacy is to convince decision/policy-makers and programme implementers to act in favour of the issue or cause being supported. The advocacy message is a brief, clear statement of the problem and a recommendation for its solution.

There are several important components of advocacy, including education and information, organising, mobilising, alliance building and networking. It is a co-ordinated process that involves planning, division of labour, flexibility, creativity and foresight, and clear vision on the desired outcomes. While advocacy is often seen as confrontational, it works even better when it involves a co-operative approach with a range of organisations and individuals.

**Advocacy is crucial in the conduct of a human rights-based response to HIV and AIDS.** It is valuable primarily for the following reasons:

- to heighten awareness of HIV and AIDS as a national and human rights issue amongst decision makers and the general public
- to contribute to a favourable and supportive environment for HIV and AIDS prevention, care and support through the formulation and implementation of relevant policies and programmes
- to mobilise the community and relevant social organisations and institutions for prevention, care and support
- to popularise technical information about prevention, care and support,
- to deal with specific community problems/issues through appropriate messages and media directed at identified target audiences.

**Basic steps to undertake advocacy work**

There are several basic steps in advocacy work that can be translated into an advocacy plan. These are:

- Step 1: identify the problem
- Step 2: conduct research on the chosen problem
- Step 3: form an alliance/network
- Step 4: develop the advocacy campaign plan.

**Step 1: Identify the problem**

Advocacy work is necessary because there are problems or issues in the community that need to be addressed. These problems or issues usually require a formulation or revision of existing policies or programmes.

**Some examples of problems/issues related to HIV/AIDS and human rights are:**

- mandatory testing as a requirement for employment
- the persistence of AIDS myths in the community
- PLHA being refused admission to health care institutions or being treated differently by health care workers due to their HIV status
- HIV-positive children being denied admission to schools because of their status
- individuals being tested without their consent or knowledge.
3. Intervention options

It may be helpful to consider the following questions when deciding what problems/issues to focus on:

- Will a solution to this problem result in a real improvement in people’s lives?
- Is the solution to this problem realistically achievable?
- Are there other groups/organisations interested in the solution of this problem?

Step 2: Conduct research on the chosen problem

Once the problem/issue has been prioritised, it is crucial to conduct research to gather relevant information that will establish the impact of the problem and help to identify a possible solution.

The research does not need to be complicated, but should answer the following questions:

- What is it about the situation that is unacceptable or wrong and needs to be changed?
- Who is affected by this problem?
- In what ways are these individuals/groups affected by this problem?
- What factors in the community influence this problem? (For example, values, attitudes, economic difficulties, etc.)
- What actions/efforts have been taken to try to address this problem? By whom? What was the reaction of the decision makers?
- What can be done to try to resolve the problem?

Step 3: Form an alliance/network

Once the research has been completed, the next step is to identify and reach out to other key and potential partners, groups and organisations. In human rights and HIV/AIDS-related problems, networking and coalition building is necessary because of the number and magnitude of the problems that exist and because there are many organisations that are interested in and committed to solving such problems.

After identifying the potential partners, hold a meeting or two to identify the problem, to go over the research and to generally get ‘buy-in’ regarding the importance of the issue. After these meetings, a core group ranging from 5-10 members (depending on the number of people who are interested, the importance of the issue, etc.) can be chosen to further develop the advocacy plan, mobilise resources and map out the strategies that are to be used. This group will also provide the day-to-day leadership.

It is important for this group to reach consensus on its mandate, overall aims and the various roles and responsibilities of its members. Members of the core group will be expected to commit to undertakings and follow through with what they have said they will do. Thus, it is important to select this group carefully, keeping in mind the workload of various organisations and individuals.

Step 4: Develop the advocacy campaign plan

One of the first tasks of the core group is to develop an advocacy plan. This can be achieved through a series of meetings, where ideas are brainstormed and agreed upon, and through consultations with individuals who are in a position to provide support and input into the design and conduct of the advocacy campaign. These may include academics, health professionals, religious leaders and media people.

Want to know more about advocacy planning? See Section 4 Tools to support interventions:

Tool 4.3 The advocacy plan.
This section is based on research done by the Siyam’kela Project. The project conducted research in three key areas – faith-based organisations (FBOs); government workplaces; and the relationship between PLHA and the media – because it believed that these institutions could play a vital role in challenging HIV/AIDS stigma. The project gathered perceptions and experiences regarding stigma from 182 participants (including 23 focus groups and 11 in-depth interviews) across South Africa. This process was guided and informed by two expert workshops, meetings of four reference groups, seven telephonic interviews with AIDS experts as a form of quality control, a literature review on stigma and a media scan. Out of this the project developed indicators of stigma to help measure stigma interventions, it documented promising practices in the three areas of influence and it produced recommendations for interventions. All of these are reflected in the discussion below.

3.5 Targeting influential institutions

3.5.1 Faith-based organisations

If you wish to work in a faith-based organisation (FBO), read this section and then decide on the approach that you would like to take. Resources and contacts are listed at the end of the pack.

FBOs have an important role to play with regards to the HIV/AIDS epidemic. They have usually been involved in caring for those living with HIV or AIDS. FBOs also have an important role to play in addressing stigma within the FBO and the community, as some of the roots of stigma lie in moral issues. We have seen that stigma is involved with sexuality and moral values and issues related to death. FBOs can address these issues. They also have a role to play in changing the attitudes of people from one of fear and rejection to one of caring and support.

There are three ways in which this section can be used. Firstly, it can be used by individual members of FBOs to influence that FBO regarding HIV stigma. Secondly, it can be used as a resource for FBOs to strengthen their HIV/AIDS work and to act against stigma in the FBO and wider community. Thirdly, the tools, issues and recommendations can be applied to other organisational settings.

Suggestions for interventions in faith-based organisations

The following strategies are discussed in this section:

- develop good policies
- build leadership
- assess levels of stigma
- involve PLHA to a greater extent
- deliver appropriate prevention messages
- raise awareness in faith communities
- move beyond providing information only
- mainstream stigma-mitigation messages
- use non-stereotypical images and concepts of PLHA
- monitor interventions for their sensitivity in relation to stigma
- adopt an inclusive approach
- re-think sexuality
- address judgemental attitudes
- use the church as a resource
- work in partnership
- use religious texts as a source of education
- bring together diverse opinions
- challenge responsibility
- challenge internal stigma
- go beyond support groups
- conduct alternative textual analysis.

Develop good policies. This can be done by discussing the issue of confidentiality, developing guidelines on confidentiality, and mainstreaming HIV/AIDS stigma and guideline policies.

Discuss the issue of confidentiality. Confidentiality is a challenge within many faith groups. The issue of how to handle confidential information, while being able to encourage the support of fellow faith members, needs to be openly discussed and possible solutions developed. Some reference group members suggested that faith leaders should ‘not collude with silence’ but should respect confidentiality if requested. Those entrusted with privileged confidential information should not disclose people’s HIV-positive status without their consent.
3. Intervention options

- **Develop guidelines on confidentiality.** Within the faith-based context, sharing personal information about community members is seen as acceptable and supportive. Members of faith-based organisations often seek and receive support from their faith community through, for example, prayer. In the context of HIV/AIDS confidentiality is extremely important. This can however often create a dilemma in an environment where personal information is freely shared. In an HIV/AIDS-supportive environment, disclosure is encouraged and it breaks the silence. Often disclosure and open communication can reduce the associated shame of the disease. It also allows a PLHA to tap into existing support services. However, in many instances faith-based organisations are not HIV/AIDS-supportive. Rather, they are characterised by stigma to the extent that PLHA may find themselves ostracised by their religious community. This has serious implications for the way in which faith leaders, in particular, need to try to balance respecting the confidentiality of a PLHA’s status and ensuring support through the congregation.

Faith leaders in the Siyam’kela research were particularly critical of how their faith groups deal with PLHA disclosure. There are no written confidentiality policies to guide faith leaders within groups included in this study, with the exception of the policy in the Roman Catholic Church related to the confidentiality of confession.

- **Mainstream HIV/AIDS stigma and guideline policies.** HIV/AIDS and stigma-reduction standards should be mainstreamed. A de-stigmatising approach to incorporating HIV/AIDS in all pastoral services, e.g. funerals, pre-marital counselling, confirmation, baptism, etc., should be spelt out in policy development. This will ensure that stigma-mitigation is taken seriously and addressed in various aspects of faith.

- **Build leadership.** There are several challenges facing faith leaders. It appears to some people that some faith leaders are unable to provide the kind of spiritual support and guidance required by the faith-community members. This is generally perceived to be the result of:
  - faith leaders being ill equipped to deal with people who turn to them for advice and support on issues related to sex and safer sex practices without taking a high moral ground
  - a sense of denial by some faith leaders that HIV/AIDS is a problem within their faith communities. This research found that this was especially prevalent in middle-class Christian and Islamic faiths.

The following table highlights key strategies and recommendations related to the building of leadership in this context:

<table>
<thead>
<tr>
<th>Strategy</th>
<th>Issues and recommendations</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Encourage leadership to take responsibility</strong></td>
<td>Important for leaders to understand the importance of tackling stigma, and taking responsibility to integrate into their faith-based leadership role.</td>
</tr>
<tr>
<td><strong>Foster leadership commitment and involvement</strong></td>
<td>The active involvement of faith leaders is highly recommended in efforts to create a stigma-free environment and should include participation in stigma-reduction interventions and message creation. This would require faith leaders to be the face of the campaign, set the scene and be role models. Such interventions could, for example, include forming support groups for those living with and affected by HIV/AIDS and should not only be limited to material support and care.</td>
</tr>
<tr>
<td><strong>Include PLHA in positions of leadership</strong></td>
<td>It is recommended that faith-based organisations consider appointing faith leaders openly living with HIV/AIDS. These leaders could be positive role models and advocates for a stigma-free environment.</td>
</tr>
</tbody>
</table>
Assess levels of stigma. It is suggested that before planning a programme to address HIV/AIDS stigma, faith leaders initiate a faith community-wide stigma assessment to gauge the extent of the problem, identify local barriers to stigma-mitigation and highlight factors enhancing mitigation. Assessment may include a survey within the faith community to learn more about members’ perceptions of PLHA and HIV/AIDS. The audit will allow faith leaders to better understand the levels of stigma within their faith community and identify critical issues that need to be addressed. The assessment and the resulted stigma-mitigation interventions should be conducted in consultation with the faith community.

Involve PLHA to a greater extent. The principle of the Greater Involvement of People Living with HIV/AIDS (commonly referred to as the GIPA principle) should be applied to faith-based organisations. The GIPA principle encourages organisations to involve PLHA in addressing the pandemic and to act as HIV/AIDS advocates for positive living.

PLHA’s expertise can be used as a resource to:
- development of HIV/AIDS-related policies and programmes
- delivery of programmes
- monitoring and implementation of programmes

By involving PLHA, the faith-based organisation’s policies will be more likely to reflect the concerns of members who are living with HIV, as well as give credibility to the HIV/AIDS interventions. PLHA could also be effective spokespersons for stigma-mitigation efforts. The use of faith members living with HIV/AIDS as positive role models will demonstrate that the environment is supportive of PLHA. Such role modelling will also begin to de-stigmatise the disease. It is suggested that PLHA be trained in:
- theological reflection on HIV/AIDS
- issues of stigma
- knowledge of rights and the pastoral standards within the faith community
- awareness of the possibilities for redress
- awareness of the services and care offered by the faith community and partner organisations
- advocacy, empowerment on advocating the role of the faith community in creating a non-stigmatising environment.

It is crucial for faith organisations to visibly involve PLHA at every level of their response to the pandemic. It is also important for faith leaders to publicly identify with PLHA. Such involvement not only helps ensure that faith organisations have an appropriate response to the pandemic, but also reduces stigma among members. Some faith leaders are themselves HIV positive. PLHA who are open about their status are crucial to reducing stigma in faith organisations.

Deliver appropriate prevention messages. There is a need to move away from understanding HIV/AIDS in terms of judgement of people’s behaviour, values and lifestyles. HIV/AIDS should not be used as an opportunity to teach about the consequences of ‘immoral’ behaviour. Faith leaders should rather spread the message of acceptance and support.

Raise awareness in faith communities. Faith communities should be sensitised to HIV/AIDS stigma, how it functions and consequences to PLHA, the faith group and society. This could be done by adding to existing HIV/AIDS awareness-raising activities.

Move beyond providing information only. Many studies have shown that information alone does not necessarily change behaviour. In addressing stigma, interventions should refer back to models that have rather focused on changing attitudes.
3. Intervention options

Awareness-raising workshops should be conducted and should include a session on unpacking underlying assumptions and beliefs that are closely linked to HIV/AIDS stigma. This would look at diversity issues: racism, sexism, and issues relating to class. A skilled facilitator is necessary to run these sessions.

- **Mainstream stigma-mitigation messages.** It is important that stigma-mitigation should not only be limited to annual events, for example World AIDS Day. It is suggested that stigma-mitigation should be integrated with other faith-based activities, e.g., Holy Communion, Sunday services, etc. Innovation is required to take moralising out of HIV/AIDS. For example, a faith group may display a big sign outside their church or mosque welcoming everyone, including PLHA.

- **Use non-stereotypical images and concepts of PLHA.** When sharing HIV/AIDS prevention messages within a faith group, these messages need to be representative of the HIV/AIDS epidemic and not use stereotypical images or concepts, such as depicting PLHA as frail and sickly or HIV/AIDS as affecting gay men only. Such images contribute to feelings of hopelessness and the perception that PLHA should be avoided. They also encourage people who do not associate themselves with the stereotypical images to feel immune to the disease and not respond to prevention messages.

Images and concepts that should be avoided include:

- those focusing on high-risk groups (e.g., truck drivers, sex workers, drug users) instead of on high-risk behaviour (e.g., unprotected sex, sharing syringes)
- images of PLHA as ‘promiscuous’ and ‘immoral’, and as a danger to members of the faith community
- images of PLHA as ‘at death’s door’
- images of PLHA as unable to live fulfilling lives because of their HIV-positive status
- understanding of HIV/AIDS as a ‘scourge’ or plague
- understanding of some PLHA as innocent, which implies that some PLHA deserve to be infected
- the language of ‘us and them’.

HIV/AIDS prevention messages should rather:

- focus on risk behaviour and not on risk groups
- show that HIV/AIDS does affect all people – all ages, cultures, genders and sexual orientations
- use positive language that is inclusive and sensitive – for example, using the term people living with HIV/AIDS instead of AIDS victims.

- **Monitor interventions for their sensitivity in relation to stigma.** It is important that all HIV/AIDS interventions are monitored for their sensitivity in relation to stigma so that such interventions do not contradict the other messages being created within the faith group.

- **Adopt an inclusive approach.** HIV/AIDS is often depicted as a disease affecting the poor, black, prisoners, women, homosexuals, sex workers or promiscuous heterosexuals. This perpetuates the idea that people who do not belong to these categories are not susceptible to infection, which, in turn may encourage risk behaviour in these groups. This ‘othering’ perception subsequently leads to stigmatisation of the groups perceived as risky. It is an important step in stigma reduction to see the whole body of the church as having HIV/AIDS. In this way HIV/AIDS will stop being the problem of just individual PLHA, and become the responsibility of the entire religious community. This approach creates inclusiveness and breaks down stigma.

- **Re-think sexuality.** It is important to move away from a view of sex as sinful. If faith organisations could promote a view of sexuality as healthy and good, it would assist their members to be less judgemental of PLHA who had contracted the virus sexually. This would in turn reduce HIV/AIDS stigma.

“All are affected by AIDS, even if all are not infected.”

Rev. Colin Jones, Anglican Church

“Responsible sexuality [is] a gift from God, something wonderful, not negative. Sex does not equate to sin. The idea that there is something wrong about sex, we believe that tradition is not a healthy one. I think a challenge is to know how to teach about sex without emphasising sin.”
Address judgemental attitudes. Another important promising practice is to develop an alternative to the model of a vindictive and judging God who uses HIV/AIDS as a punishment for human sin. The idea of a compassionate God is to be preferred as it reduces the judgementalism of members of faith groups regarding HIV/AIDS. In this way stigma is also reduced.

The Church often interprets the Bible in a narrow way, and this has to change.

"Talking about HIV/AIDS in terms of sin is not helpful as it puts PLHAs into a situation of feeling judged."

In HIV/AIDS it is important to engage in both practical care, as well as reflection at the intellectual and theological levels on the meaning of the disease.

It is important to speak the message of responsible morality regarding sexual behaviour.

It is necessary to challenge gender practice in FBOs that disempowers women in order to show people what we want to move towards: building strong women who make choices for themselves.

Use the church as a resource. The church, even in rural areas, has many resources which could be utilised for HIV/AIDS work.

"Even in the remotest villages there is access to a church ... we can use these facilities for AIDS work, educating people to spread the message. We can also use our resources in the community, for instance, caring for people living with HIV/AIDS by providing home-based care support, and by providing spiritual and emotional support to people. Orphan children are another important area."

Use religious texts as a source of education. FBO approaches to PLHA need to be based on a long process of reflection, which starts with finding a sound theology for approaching HIV/AIDS. There is a need for FBOs to return to a close study of religious texts in order to reduce HIV/AIDS stigma.

In the Christian tradition, the gospels are particularly challenging to those who stigmatise PLHA.

"I think if you read Matthew 25 you will find it very hard to engage in condemnation of people who are HIV-positive ... I think in that passage, if there's any judgement, it is not on the people that are infected and affected by HIV/AIDS, an element of judgement is towards how the church responds to people that are affected by HIV/AIDS."

Work in partnership. Another important stigma-mitigation practice is for faith organisations to work together in partnership to address the HIV/AIDS pandemic. This is already happening between the mainstream Christian denominations. However, partnerships needed to be extended to include smaller and traditional African churches, as well as groups representing other faiths.
3. Intervention options

- **Bring together diverse opinions.** There is a need to reconcile those in FBOs who have strongly opposing views of the HIV/AIDS pandemic. An important role is played by what can be described as ‘the ministry of reconciliation’ in some Christian churches in alleviating stigma. In practice this means bringing together in a religious service PLHA and members who engage in stigmatisation in order to build new and healed relationships between them.

- **Challenge responsibility.** Stigma reduction can also occur through making members of faith organisations aware that the HIV/AIDS pandemic is the responsibility of everyone. All are affected. In some Christian churches the extensive involvement of the church in all aspects of HIV/AIDS derived from an understanding of the faith community as part of the body of Christ.

- **Go beyond support groups.** The involvement of a FBO must extend beyond the integral inclusion of PLHA to include a programme for children orphaned by AIDS, emergency food relief for the destitute, condom distribution, and an education and awareness programme. The FBO must also provide a skills-training programme for women in basic home-care and training for health care workers in HIV/AIDS.

- **Conduct alternative textual analysis.** It is important to provide faith leaders with an alternative, non-stigmatising perspective on HIV/AIDS. Such a perspective could be derived to a significant extent from texts from key religious books which support and encourage a caring response to PLHA in religious groups. Such texts allow leaders and members of faith groups to engage in a more compassionate response to members who are HIV positive, as they will teach a different perspective to the stigmatising discourse prevalent in many faith groups.

- **Challenge internal stigma.** Passages from holy texts have the potential to challenge the internalised stigma of PLHA who are members of faith organisations. Such passages have an enormous power to reduce HIV/AIDS stigma.

- **Our reading can never limit the Qur’an.** The Qur’an is miraculous because of its ability to transform the reader. It is not a passive text but has an inexhaustible number of readings, depending on the reader’s context. On the contrary, depending on the reader’s God consciousness, the text will surface meanings hitherto hidden.

- **In the midst of the challenges of HIV/AIDS, we can be assured that God still loves us ... God promises to bring good results out of our difficult situations. HIV affects the body but hope is found in the soul.”**

- **“In the Muslim community the study of compassion addresses the discrimination and prejudice the Muslim person living with HIV faces. It also addresses the issue of justice ... we cannot be judgemental towards people who have been diagnosed with HIV/AIDS.”**

- **[The faith community is] “... the body of Christ which means that there is the whole question of us belonging to one another and if one suffers, everyone suffers. There is a call to really carry each other’s burdens and be involved.”**

- “Our reading can never limit the Qur’an. We are children of God, regardless of who we are and what we are. So that is the most important thing that is being taught here - to destigmatise and to love one another.”

- **What is mostly taught is love and that God loves us all. We are children of God, regardless of who we are and what we are. So that is the most important thing that is being taught here - to destigmatise and to love one another.”**

- **“In the midst of the challenges of HIV/AIDS, we can be assured that God still loves us ... God promises to bring good results out of our difficult situations. HIV affects the body but hope is found in the soul.”**

- **“It is only when we are able to establish the right balance between jalal (a strong sense of justice) and jamal (an unlimited compassion), that we will be able to perhaps display what Allah intended of us - kanal (perfection).”**

- Rev. Martin Nkutha, Church of Christ in Southern Africa.
3.5.2 The media

The media has enormous power to influence people’s knowledge and attitudes. Its role in terms of shaping values and perceptions means that the media can significantly contribute to the increase or reduction of stigma. News is shaped by many people – journalists, interviewers, editors, owners and other stakeholders – all of whom influence the content, bias and tone of an article or programme. For this reason, combined with the fact that HIV and AIDS is just one of the many topics covered, it is not realistic to expect the media to always communicate the information in the manner or the extent we would like. The media is driven by sales and profit, and as such, prioritises stories which sell, not necessarily those which educate. In addition the years of the epidemic have resulted in ‘AIDS fatigue’ where the public is no longer interested in stories about HIV and AIDS.

Given this, it is now as important as ever to find effective ways to influence the media. The aim is to get the media to give HIV and AIDS more extensive coverage, to portray the epidemic and people living with HIV in a human and non-stigmatising way, to promote rights, dignity and acceptance, to provide a forum for advocacy, and for the media to be a source of accurate and empowering information.

There are two major approaches:

- how people working in the media can work against stigma
- how people outside the media, including PLHA, can work together with the media to address stigma.

Guidelines for PLHA on working with the media to reduce HIV/AIDS-related stigma

Are you ready to disclose publicly?

When a PLHA works with the media, the question is going to come up: Is this person living with HIV? If the person is interviewed by the media about HIV, then listeners, readers or viewers will want to know whether the person is living with HIV. So the first very important issue is that of personal disclosure.

If you want to work with the media you must be sure that you are psychologically ready for everyone to know that you are living with HIV. Internal stigma, which occurs when a PLHA is ashamed of living with HIV, was discussed earlier. The PLHA who wants to work with the media must have worked through the problem of internal stigma.

It is also important that the PLHA has disclosed her or his status to family, friends and work colleagues before working with the media. Family and friends may be very upset if they learn of the person’s HIV status for the first time through the media. For some people, disclosing HIV status can have very serious consequences. If, for example, a young person is living with his family and the family do not know of his or her HIV status and they then hear it on the radio they might evict person from the house. Sometimes the family knows the HIV status but does not want the community to know, so they may be angry if the person discloses publicly. So it is important that the PLHA talks to family and friends first before disclosing in the media.

It is possibly also not a good idea for someone who has recently found out that they are living with HIV to do interviews with the media until they are ready for the stress and pressure which this can cause.
3. Intervention options

- **Establish a personal support base**
  
  Often dealing with the media and disclosing publicly is very stressful. It is important for a PLHA who is dealing with the media to have a strong support system. The PLHA should have strong support from family and friends. It is also important that these people support the PLHA in the decision to work with the media and perhaps disclose HIV status publicly.

- **Understand the power of the media**
  
  The media is very powerful and can influence many people. However, this still has to be done with self-awareness, judiciousness and caution – as much as the media can give the interviewee a sense of fame and importance, it can also leave one feeling exposed and vulnerable.

- **Acknowledge media realities**
  
  The media has to cover many stories and it is not possible for journalists to have a good understanding of everything. So it is important for the PLHA to brief the journalist or the interviewer because they usually have more correct information. They need to point out to the media how stigma is developed, they must point out when the interviewer uses words which are hurtful, and they must work with the journalist to reduce stigma. Remember that it is better to work with people when they are wrong rather than to attack them.

- **Get training**
  
  The above anxieties can be dealt with through training on handling the media. This assists in planning, preparation, briefing the reporter, fielding difficult questions, seizing the moment to get your message across, and getting your messages across in a small period of time.

- **Know what the interview is about**
  
  For a person being interviewed by the media it is important for them to know what the interview is about so that they can make sure that it is a subject that they want to discuss and also so that they can decide whether they are able to do the interview properly. It is their right to ask the journalist or interviewer what the interview is about and, if possible, they should ask the journalist for a list of questions that are going to be asked in the interview. Once they know this then they must make a decision whether they want to do the interview and whether they are capable of doing the interview. This also allows the person to prepare for the interview because knowing the questions means they can start to prepare the answers. But the person being interviewed needs to be careful, because sometimes interviews don’t go the way they were planned and some unexpected questions may be asked.

  The person being interviewed needs to request to work with the journalist/reporter to determine what questions will be asked and to edit the interview before its final production. This may not always be possible but it is useful if they can get the journalist to agree to this.

- **Confront fear of the media**
  
  People are often afraid to work with the media as it can be very intimidating. It is therefore important that people confront this fear. For PLHA, this fear is often connected to internal stigma. Working with the media can be difficult but with careful preparation and practice it can be a very rewarding experience.

“**If recently diagnosed, it’s important to come to terms with the disease first before doing any talking to the media. Avoid them at this early stage. Don’t talk to the media until you are ready.**”

Ms Pinky Mabula Tiro

“**The media can build you up and they can break you. So you must treat them with lots of caution. You can’t talk without thinking very, very carefully about what to say.**”

Ms Pinky Mabula Tiro

“**When dealing with the media one needs training. You need to learn how to be vocal. You need to be prepared, know exactly what you are going to say because if you are not prepared at times you end up dealing with emotional issues rather than dealing with the real issues at hand.**”

Mr Mkaase Nkho, ACCT, Baragwanath Hospital

“**You need to break the fear of PLHA raising their issues with the media … you need to know that it is not always a bad experience to deal with the media. It can be very rewarding too. We must not be inhibited by the fear of what can go wrong.**”

Mr Mkaase Nkho, ACCT, Baragwanath Hospital
Tell positive stories

The media often focuses on negative stories and this often increases stigma. It is therefore also important that PLHA focus on giving positive aspects of living with HIV. It is important to counter-balance stories of struggle, suffering and problems with those of hope, courage, individual and collective action, and empowerment.

Prepare for interacting with the media

Preparing for an interview is very important. It makes all the difference between a good interview and a bad one.

What a person needs to prepare:

- Know what the interview is about and if possible what questions are going to be asked.
- If the person doesn’t know the questions in advance, they should try to think of some of the questions which they may be asked.
- Remember that if the interview is opened up to questions from the audience there may be questions which they were not expecting.
- Make sure to have the correct information to answer the questions.
- A PLHA needs to decide clearly what personal information they are willing to give.

One of the problems about stigma is that many people are not aware that it exists and are not aware that it is a problem. So if we want to fight stigma, it is important that we talk about it directly.

Put stigma on the agenda

One of the problems about stigma is that many people are not aware that it exists and are not aware that it is a problem. So if we want to fight stigma, it is important that we talk about it directly. It is important to raise the issue of stigma in interviews. The interviewer may need to be educated about the challenges related to stigma, and the role the media can play in reducing it. An important aspect is the language which the media uses in relation to HIV and AIDS, which can be hurtful and stigmatising.

Include the voices of ordinary people living with HIV

Usually it is the same PLHA who are repeatedly interviewed by the media. It is important that many voices are heard and that many people get to tell their story and give their information. It is also important that a broad spectrum of people are given the opportunity to tell their story and not only the articulate and well educated.

Tell positive stories

The media often focuses on negative stories and this often increases stigma. It is therefore also important that PLHA focus on giving positive aspects of living with HIV. It is important to counter-balance stories of struggle, suffering and problems with those of hope, courage, individual and collective action, and empowerment.

Having a say in the final product

Where possible, it is useful to see a draft of the final product before it is broadcast or published to correct any mistakes or wrong impressions. Focus specifically on any aspects which could increase stigmatisation.
3. Intervention options

Additional guidelines for media practitioners to reduce HIV/AIDS stigma

- Take a historical perspective.

Language is extremely important in influencing people’s perceptions. In addition languages (and especially African languages) provide a culturally rich resource. There is a strong tradition in African languages of naming, praising and respecting. It is important that we understand the power of these traditions in influencing perceptions.

#### Naming stigma

Naming in African languages is always significant, with most given names having a meaning. The names given to HIV/AIDS are similar to those used when talking about powerful leaders and outstanding personalities – complex, compound names normally heard in praise poetry, in the reciting of genealogies.

Compare the praises of a great fighter, Mqikela Ndayi: USinandle, ungqamb’ esililini (he is a rifle speeding to its target) (in Opland 1998:306) with the name for AIDS, the great killer: UDubul’ egeqa (he who shoots to kill).

People react emotionally to praise names which invoke respect and, in some instances, fear. HIV/AIDS must be feared and therefore its personification and praisenames are appropriate.

Interestingly, however, in ordinary discourse and in marketing and educational campaigns, no one has thought to give the condom a praise name. There are no advertisements or posters that refer to the condom as UMsindisi weSizwe (The Saviour of the Nation) or other similar praise names that could so easily be coined.

In fact, not only are condoms not given praise names, they are rather trivialised, likened to everyday, commonplace objects such as jackets (idyasi), gumboots (igambutsi) and baby bags (mokotsla wa bana). Similarly, while there are ways of talking about people living with AIDS, there are no praises for them. There are no names to inspire, to suggest strength and survival in the face of all odds. Rather, a PLHA is someone who has “caught it” (ubhaqile), or who has had “a hot coal fall upon himself or herself” (uwelwe lilahle).

In African languages, Dowling argues, there are two categories for HIV/AIDS that encourage the ‘victim’ view, those being HIV/AIDS as personified killer and HIV/AIDS as taboo. There is yet another category that takes its references from popular culture, and almost pokes fun at the prevalence of the disease, branding it as a game, a ride on an overcrowded train.

**HIV/AIDS as personified killer:**

Examples of this include UMabulalabhuqe (the indiscriminate killer – Zulu); UDubul’ egeqa (the one who shoots to kill – Xhosa); UGawulayo (the one who chops down – Xhosa); UQedisizwe (the finisher of the nation – Zulu) and UMashayabhuqe (the beater-up of people – Zulu).

Names for HIV/AIDS falling into this category are often compound nouns made up of verb-verb combinations, for example bulala (kill) + bhuqa (trample down, break down, cause havoc), or verb-noun combinations such as bulala (kill) + isizwe (nation).

**HIV/AIDS as taboo:**

“There is such a sense of awe surrounding taboos that they may not be named or discussed. This has led to the development of a special language called (uku)hlonipha ... it is made up of substitute words and is a polite and reverent language used only for taboos and the ancestral spirits.” (Pinnock 1988:61).
Language and information on HIV and AIDS as presented in the media have an important impact on the development and experience of stigma. The media is a powerful tool because of its reach and influence. It can influence people’s opinions, attitudes and behaviour. The media can make messages about HIV and PLHA non-stigmatising. Media professionals can examine and modify the language used in media to ensure that it does not portray HIV and people living with HIV in negative stereotypical ways.

- **Examining the language of media messages**

Language and information on HIV and AIDS as presented in the media have an important impact on the development and experience of stigma. The media is a powerful tool because of its reach and influence. It can influence people’s opinions, attitudes and behaviour. The media can make messages about HIV and PLHA non-stigmatising. Media professionals can examine and modify the language used in media to ensure that it does not portray HIV and people living with HIV in negative stereotypical ways.

- **Provide accurate information**

It is important to provide accurate, up-to-date and complete information. The wrong information can lead to greater stigma. It is also important to present information in ways which are not sensational.

- **Do not reinforce misperceptions**

There are many misperceptions about HIV and PLHA. There are also many stereotypes about who gets HIV and the lives lead by PLHA. Images and concepts that should be avoided include:

  - those focusing on high-risk groups (e.g. truck drivers, sex workers, drug users) instead of on high-risk behaviour (e.g. unprotected sex, sharing syringes)
  - images of PLHA as ‘promiscuous’ and ‘immoral’, and as a danger to members of the faith community
  - images of PLHA ‘at death’s door’
  - images of PLHA as unable to live fulfilling lives because of their HIV-positive status
  - understanding of HIV/AIDS as a ‘scourge’ or plague
  - understanding of some PLHA as innocent, which implies that some PLHA deserve to be infected
  - the language of ‘us and them’.

HIV/AIDS prevention messages should rather:

  - focus on risk behaviour and not on risk groups
  - show that HIV/AIDS does affect all people – all ages, cultures, genders and sexual orientations
  - use positive language that is inclusive and sensitive - for example, using the term ‘people living with HIV/AIDS’ instead of ‘AIDS victims’.

Unfortunately the messages which we want to encourage regarding HIV, are sometimes contradictory:

- on the one hand we want to encourage support and caring for those living with HIV and so we may tend to have a negative focus on the difficulties of living with the virus. But on the other hand we want to encourage a message of hope that people living with HIV are able to live fulfilling and productive lives
- on the one hand we want to encourage the message that HIV is dangerous and that if you do not protect yourself you may become HIV positive with very negative consequences for your life. But on the other hand we want to say that even with HIV, you can live a fulfilling life.

Clearly the messages that are portrayed through the media have to be carefully balanced.
3.5.3 The workplace

The workplace is very important in our efforts against HIV/AIDS: there is a ‘captive’ audience, there are often resources to support activities, and it is mutually beneficial as the employer needs a healthy, productive workforce.

Guidelines for stigma mitigation in the workplace

Policy
- **Conduct an HIV/AIDS policy analysis**
  It is recommended that an HIV/AIDS policy analysis be conducted by all companies or government departments. Such an analysis should focus specifically on the extent to which they address HIV/AIDS stigma. The analysis should also assess whether policies either produce or reinforce HIV/AIDS stigma. Once this has been conducted policies should be amended or sections added to existing policies to address HIV/AIDS stigma.

- **Inform employees of HIV/AIDS stigma-mitigation policies**
  The policy relating to stigma should be brought to life through presentations and workshops. Employees need to be aware of the policies in place in order to feel supported and in order to understand the consequences of discriminatory behaviour.

Leadership

In many organisations, businesses and government departments there are leadership challenges related to HIV and AIDS:

- insufficient support and commitment from senior managers to HIV/AIDS issues
- a perceived ignorance of and lack of interest in HIV/AIDS issues by senior management
- the responsibility for management of HIV/AIDS strategy has often been shifted to the human resources directorate with limited or no involvement of other business units
- insufficient communication between HIV/AIDS coordinators and senior management, which has led to the questioning of the source of information on HIV/AIDS by employees.

Strategies to deal with leadership challenges at the workplace

- **Mainstream HIV/AIDS stigma-mitigation interventions**
  It is recommended that senior management take the lead for HIV/AIDS stigma-mitigation specifically, and for HIV/AIDS more generally. This would include both supporting and monitoring HIV/AIDS and stigma-mitigation policies and programmes. By actively taking responsibility, leaders may be able to bridge the perceived divide between staff and themselves. Visible management involvement has the potential to dispel the myth that the higher ranks of staff are themselves immune to HIV/AIDS, and sends out an important stigma-mitigation message that HIV/AIDS affects all.

- **Involve leadership directly**
  It is crucial that management is committed to creating an environment that is free of HIV/AIDS stigma within their departments. One way this commitment could be demonstrated is through direct leadership involvement. This would not only involve visible leadership, but also active participation in HIV/AIDS stigma mitigation interventions at various levels. Leaders need to be the face of the campaign and to lead by example.

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"The policy is just there in name only. It’s there but nobody bothers to read it, and it is not enforced. So it’s like the policy is not really there."

- **Mainstream HIV/AIDS stigma-mitigation policies**
  Just as all other aspects of HIV/AIDS policies should be mainstreamed, so should those related to stigma. Stigma-mitigation policies should be reflected in, for example, the content of communication strategies and strategic plans. This will ensure that stigma-mitigation is taken seriously and is addressed within the workplace.

- **Monitor the implementation of policies**
  All HIV/AIDS policies, and especially those relating to stigma-mitigation, should be monitored so that the policy does not only exist on paper but is put into action. This will also give the policy the necessary credibility.
- **Provide leadership training**

There needs to be an effort to build the capacity of the leadership to effectively create anti-stigma messages and take responsibility for the HIV/AIDS stigma-mitigation process. Training should include:

- sensitising managers to HIV/AIDS stigma by focusing on how it develops and what the consequences of stigmatisation are for PLHA in the workplace
- exploring their own attitudes and prejudices and linking them to HIV/AIDS stigma.

- **Include PLHA in positions of leadership**

It is recommended that qualified senior managers living openly with HIV/AIDS should be appointed. These leaders could be positive role models and advocates for an HIV/AIDS-friendly environment.

- **Focus on employee needs**

The workplace is an ideal setting for HIV/AIDS prevention programmes, as well as for the provision of treatment, care and support to employees infected and affected by HIV/AIDS.

- **Assess levels of stigma**

Before planning an intervention to address stigma, it is suggested that the organisation conducts a stigma audit to assess the extent of the problem, as well as the local barriers and enhancing factors of stigma mitigation (see monitoring and evaluation section below).

The audit may include a survey of employees to assess their perceptions of PLHA and HIV/AIDS and how these perceptions have influenced their responses to PLHA within their departments. The audit will allow managers to assess the levels of stigma and to identify critical issues within various departments that need to be addressed. After the audit has been completed the findings should be shared with staff members. During this feedback session staff, especially PLHA, should be included in planning interventions that address stigma-mitigation.

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**The following programmes are suggested:**

<table>
<thead>
<tr>
<th>Programmes</th>
<th>Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td>Educational programmes</td>
<td>These include peer education programmes, distribution of HIV/AIDS leaflets and posters, and utilising the internet to emphasise the promotion of healthy lifestyles.</td>
</tr>
<tr>
<td>Awareness raising programmes</td>
<td>Promote awareness through the use of stationery with red ribbons. Highlight special events – for example candlelighting ceremonies, World AIDS Day and condom week. Bring in external PLHA consultants to give talks on HIV/AIDS. Formal HIV/AIDS messages which can be promoted include:</td>
</tr>
<tr>
<td>- condomise</td>
<td></td>
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<tr>
<td>- the organisation provides support</td>
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<tr>
<td>- you will not be discriminated against if you are HIV positive</td>
<td></td>
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<tr>
<td>- support people living with HIV/AIDS</td>
<td></td>
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<tr>
<td>- HIV/AIDS is real</td>
<td></td>
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<tr>
<td>- we can do something if we know your status</td>
<td></td>
</tr>
<tr>
<td>Counselling services</td>
<td>These include voluntary pre- and post-HIV test counselling and supportive counselling linked to employee assistance programmes.</td>
</tr>
<tr>
<td>Prevention programmes</td>
<td>These include condom distribution programmes.</td>
</tr>
<tr>
<td>Support groups</td>
<td>These can help those living with and affected by HIV/AIDS and manage the needs of staff living with HIV/AIDS – aligning jobs to the needs of ailing staff.</td>
</tr>
</tbody>
</table>
3. Intervention options

- **Involve PLHA to a greater extent**
  One key recommendation is that people living with HIV/AIDS should be involved in all HIV/AIDS-related policy development, implementation and monitoring of programmes. People living with HIV/AIDS have unique experiences and expertise, which could be used as a resource. By involving PLHA, workplace policies will be more likely to reflect the concerns of employees living with HIV, as well as give credibility to the HIV/AIDS programmes. PLHA could also be effective spokespersons for stigma-mitigation.

Positive role models of employees living with HIV/AIDS within the workplace will demonstrate that the environment is supportive of PLHA. Such role models will also begin to de-stigmatise the disease by, for example, proving HIV/AIDS myths incorrect. The principle of the Greater Involvement of People Living with HIV/AIDS (GIPA) should be applied more widely in the government workplace. The GIPA principle encourages workplaces to involve PLHA themselves in addressing the pandemic and to so enable PLHA to act as HIV/AIDS advocates for positive living. PLHA have unique experiences and expertise that should be used as a resource.

To achieve the increased participation of PLHA in workplace-based programmes, it is suggested that PLHA be trained in:

- disclosure
- issues of stigma
- coping skills to assist with the discovery of, and acceptance of, their HIV-positive status
- advocacy
- presentation and public speaking skills
- peer counselling
- knowing their rights and the HIV/AIDS policies or policies that relate to HIV/AIDS within their departments
- making them aware of their redress possibilities
- referral services – being aware of the services and care offered by their department and partner organisations.

- **Provide training and awareness raising on stigma**
  Staff at all levels should participate in training, sensitising them to HIV/AIDS stigma, how it functions and its consequences for PLHA, the workplace and society. Existing training should be participative and not lecture-based. Many studies have shown that information does not necessarily change behaviour. In addressing stigma, interventions should refer back to models that have rather focused on changing attitudes. Training should include unpacking underlying assumptions and beliefs which are closely linked to HIV/AIDS stigma, such as diversity issues, racism, sexism, and classism. This training will require skilled facilitators.

- **Commit to visible care and support of PLHA**
  Staff who are living with HIV/AIDS need to know that if they disclose their status in the workplace, they do so in a caring environment. If care for and support of PLHA is clearly visible, PLHA will be more likely to make their HIV status known.

- **Mainstream HIV/AIDS stigma-mitigation messages**
  It is important that the stigma mitigation messages are not only limited to annual events or only aimed at certain staff levels. It is suggested that the message should be integrated with other workplace HIV/AIDS messages and that creative opportunities to spread the stigma-mitigation message should be encouraged. HIV/AIDS stigma-mitigation training, for example, could be held during staff meetings so that it is integrated within daily routines.

- **Use non-stereotypical images and concepts of PLHA**
  When sharing HIV/AIDS-prevention messages within the workplace, it is strongly advised that these messages are representative of the HIV/AIDS epidemic and not presented by stereotypical images or concepts, such as depicting PLHA as frail and sickly, or HIV/AIDS as a gay men’s disease. Such images and concepts add to the feeling of hopelessness and the perception that PLHA should be avoided. They also allow people who do not associate themselves with the stereotypical images to feel immune to the disease and not respond to prevention messages.
Monitor interventions for their sensitivity in relation to stigma.

It is important that all HIV/AIDS interventions are monitored for their sensitivity in relation to stigma so that such interventions do not contradict other stigma-mitigation messages within the workplace.

Challenges for HIV/AIDS workplace programmes

Despite these interventions and messages, very few employees have openly disclosed their HIV status in the workplace. Some participants in the Siyam’kela Project mentioned that partial or informal disclosure does, however, occur in smaller groups. Some people are perceived to be taking greater precautions against contracting HIV because they have been personally affected by HIV/AIDS.

According to research findings, the programmes seem to be hampered by several key issues:

- Apathy amongst employees concerning HIV/AIDS-related issues, especially among white and/or middle class staff, is an example of the consequences of ‘othering’, which has made some groups feel that they are not at risk of HIV infection.
- Apathy can also be linked to the HIV/AIDS information fatigue of many employees.
- A further challenge in running interventions has been employees’ fear of stigmatisation and discrimination. As a result, very few employees have disclosed their HIV/AIDS status.
- Many HIV/AIDS co-ordinators have limited resources and competing demands, since HIV/AIDS is only one of many other responsibilities they have to spearhead within an already challenged department.

Many HIV/AIDS co-ordinators were critical of the present approach taken by departments, recognising that their current training does not enable them to change people’s attitudes or behaviour. Training is lecture-based and there seems to be a lack of creativity when presenting the training. Furthermore, only a selected group of people is sent to the training.
3.6 Promoting human rights literacy

Research has shown that whilst the theory of human rights is well intentioned, it does not always filter down to the grassroots level. This section is based on work done by the Tswelopele Project\(^\text{16}\), which has done extensive research on HIV/AIDS, human rights and stigma.

The Tswelopele Project found that both awareness and the application of human rights was seriously lacking in the communities where their research was conducted.

The reasons for this include:

- the fact that there were simply no opportunities for people to be exposed to these ideas
- there was a difficulty in making rights real in an environment of high unemployment and poverty
- there was cynicism and lack of faith in government departments and employees
- the community was not aware of how to deal with rights violations
- the community sometimes saw human rights as a problem rather than a solution – for example confidentiality and informed consent were seen as a barrier to openness and people supported the idea of routine testing
- there was fear of stigma and discrimination so that rights violations were not reported
- some people such as police officers felt that communities were not educated that rights need to be accompanied by responsibilities.

Recommendations that came out of the project include:

- update and continue education and awareness raising on human rights, including ‘forgotten’ groups such as older women in the community who bear the burden of care – these programmes should focus on the basic principles of human rights, how to recognise human rights violations and where to go for assistance
- education on the basic facts of HIV and AIDS for key role players in a community – the police, traditional leaders, the municipality and faith-based organisations – as well as education on human rights and rights violations
- training for municipal officials on their roles and responsibilities as elected officials to alleviate rights violations
- capacity building of local AIDS councils so that they can function more effectively
- basic HIV/AIDS education and awareness of human rights violations for family members of PLHAs through social clubs, clinics and drama
- training in ethics and rights for health care workers – this could include reviewing the Batho Pele principles and the importance of addressing stigma
- plain language materials made available to community members – this should cover the Bill of Rights and laws that protects the rights of PLHA
- mobile units of the Departments of Social Welfare and Home Affairs could be used by the Human Rights Commission to popularise human rights and the work of the commission
- AIDS service organisations – especially those involved in home-based care – should be trained to identify and make referrals on human rights violations
- community-based human rights champions – such as ward committee members or other community leaders – could act as intermediaries to find solutions for perceived or real human rights violations.

As a result of this research, the Tswelopele Project developed a training manual on stigma and human rights. Some of the exercises have been used in the Stigma Resource Pack. One of the main aims of the next phase of the project is the training of para-legals, people in the community who understand human rights and rights violations and who can deal with community members. These para-legals contribute to human rights literacy in the community and can allow enacted stigma to be challenged in a variety of ways.

The Tswelopele Project also highlighted the need for ongoing general as well as targeted training (i.e. for specific groups such as health care workers, the police, church groups, etc.) on HIV as a human rights violation.

It is clear that, without being able to ‘name it’ (label the violation that occurred), that people will be unable to ‘claim it’ (seek redress). Ensuring that rights are respected, protected and promoted are the key elements of the rights-based approach, which has been discussed in a previous chapter.

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\(^{16}\) The Tswelopele (moving forward) Project researched human rights in Tshwane District, in the North West and Gauteng Provinces in South Africa. For more information see www.csa.za.org or contact the CSA (information under contact in Section 10.)
3.7 Providing credible information

Research has shown that the root of stigma often lies in ignorance. This ignorance can be due to:

- lack of knowledge about the problem of stigma and lack of understanding that certain behaviours are stigmatising and discriminatory
- lack of knowledge about various aspects of HIV and AIDS which leads to unrealistic fears and misunderstandings about becoming infected and living with HIV/AIDS.

Education regarding stigma

Education regarding stigma is not the final objective that we want to achieve. Rather, we want to use education to change people’s attitudes, values, beliefs and behaviours. We want to educate so that people have a proper, non-stigmatising attitude towards HIV and AIDS and PLHA and so that their behaviour is supportive, sensitive and caring rather than stigmatising and discriminatory.

Education about stigma needs to focus on the following:

- to develop an understanding of stigma, its impact and why it is important to address stigma in the community
- to make people aware of the types of attitudes, words and behaviours that are stigmatising
- to convince people of the importance of tackling stigma.

Education about the facts of HIV and AIDS

HIV stigma is rooted in both fear and ignorance. Research has shown that everyone has some information about HIV and AIDS but few have enough information to overcome irrational fears associated with HIV and its transmission. Most people know that HIV can be transmitted through sex, but few are convinced that they are not also at risk through non-sexual ‘casual contact’. As a result they may fail to distinguish real risks from imagined risks. For instance, they may avoid a fellow (bus) passenger thought to be HIV positive for fear of touching him, coming into contact with his blood in the event of an accident or cleaning the bed sores of a PLHA in the home. Their fear of ‘casual contact’ will often lead to isolation and segregation of PLHA – isolating them from others, giving them separate plates and cups, and a separate room.

Attitudes toward PLHA are also affected by incorrect and incomplete knowledge. Many believe that a person who tests HIV positive will get sick and die immediately. Many assume that secondary infections (such as TB) cannot be cured in an HIV-positive individual. Not knowing that a PLHA can lead a productive and long life, they stigmatise and de-humanise PLHA, calling them ‘walking corpses’ (people who are about to die) and treat them as ‘useless’, ‘unproductive’ and ‘burdens on the family’.

On the last day of a six-week AIDS course in Zambia, which included many sessions on AIDS facts, a man said: “I don’t believe this HIV business. The real reason people are getting sick is kufunga (sickness attributed to a man sleeping with a woman who has had a miscarriage)”. The trainer threw up her hands and said, “How can you say this after all of the things I’ve taught you?” The man replied, “Okay, if you want me to say HIV is the cause of the sickness, I’ll say it, but I don’t really believe it.”

So lack of knowledge leads to stigma. But knowing facts is only half the story! People may know the basic HIV and AIDS messages, but often don’t believe them.

- People’s knowledge about HIV and AIDS is often rote knowledge - information which they have received, but not internalised. They know them as simple slogans or rules, for example, “You can’t get AIDS from shaking hands”, which they are expected to follow without any real understanding. The rote knowledge does not stop people fearing getting infected through casual contact. People are not willing to gamble their lives on an untested piece of rote knowledge which they hardly believe.
- For full understanding people need to compare, test and question the information they have heard with their own experience, beliefs and common sense.
- The correct information people have received may be contradicted by other beliefs – what they have learned from the family, clan, tribe, church, school or media, as well as their own life experiences. Often these popular beliefs (e.g. that HIV is caused by sleeping with a woman who has aborted) are more persuasive than the facts provided by AIDS educators.
3. Intervention options

One HIV stigma study identified knowledge gaps in the following areas:

- how HIV is transmitted and is not transmitted
- the difference between HIV and AIDS
- what it means to live with HIV – opportunistic infections can be treated
- an HIV-positive test result does not mean instant death
- PLHA can be as productive as any other members of society.

Need to know more about facts and key issues related to HIV and AIDS?
See Section 7 Additional information:

7.10 Providing credible information - an overview of HIV and AIDS: facts and issues; 7.11 QQR and 7.12 Frequently asked questions about HIV and AIDS.

Here are some suggestions on ways to engage in this educational process:

- Create safe opportunities for participants to raise all the fears, concerns, and questions they have about HIV/AIDS.
- Assess participants’ knowledge level about HIV/AIDS: find out what they know and what they don’t know about HIV and AIDS, beliefs and misconceptions.
- Provide information geared directly to people’s fears and misperceptions about getting HIV through casual contact. Provide information to challenge misperceptions and help participants fully understand HIV transmission and make informed decisions about different risk situations (accidents).
- Provide information on progression of the illness and treatment for PLHA in order to counter views that people who are HIV positive will die immediately.
- Provide the information in a practical and participatory learning process which allows people to internalise the information – to discuss it with their peers, connect it to their own ideas and experience, and apply it to the situations they regard as risky in their daily lives.
- Analyse and challenge incorrect popular beliefs. “Every time you have sex with a woman your viral load goes down.” “Sleeping with a virgin cures AIDS.” “AIDS is caused by sleeping with a woman who has had a miscarriage.”
- Emphasise common sense regarding hygiene. Example: we would not share razors with other people; and we would not drink from a cup or eat from a plate which has blood on it. This is common sense.
- Emphasise that sex is the main route for HIV. Explain that even though we are discussing non-sexual (casual) contact, people's biggest risk in getting HIV is having unprotected sex. HIV is transmitted mainly through sex. If appropriate, ask participants whether persistent belief in casual transmission somehow makes it easier to justify unsafe sex.

A new approach is needed which provides more than facts and information, but also helps people to own and internalise their knowledge. This requires a sensitive educational process which goes beyond information-giving, and encourages people to explore their fears, prejudices, and feelings; and raises awareness about stigma which can be then translated into action.
3.8 Running experiential workshops

One of the best ways to change people’s attitudes and behaviours is through experiential training. With experiential training we want to get people to think through the issues for themselves. We also want to put them through an experience which shifts them emotionally. Through taking this approach it is more likely that they will change their attitude and behaviour. We also want people to change their attitude and behaviour towards regarding HIV/AIDS:

- We want people to be accepting, supportive and caring of PLHA rather than rejecting and stigmatising.
- We want people to have an attitude where they take the risk of HIV seriously but do not have irrational fears about becoming infected.
- We want PLHA to have an attitude towards themselves which recognises themselves as important and valuable people. We want to help PLHA to address internalised stigma and to build self-esteem and self-confidence.
- We want PLHA to recognise that they can live fulfilling and satisfying lives.

Start with yourself

If you are a trainer, we recommend that you use the Stigma Resource Pack yourself to help you reflect on your own attitudes, values, beliefs, use of language and behaviour towards PLHA before you work with others.

Integrate stigma awareness into other AIDS education activities

The Stigma Resource Pack focuses solely on stigma and workshops can be organised on this theme alone. But we would also encourage you to integrate these sessions into other AIDS education activities. The aim should be to ‘mainstream’ stigma - to make it a regular part of all educational activities for AIDS educators and communities.

What does the Stigma Resource Pack provide for trainers?

For trainers the resource pack provides the following:

- information about the facts of HIV and AIDS – as we know good, credible information is a part of addressing stigma
- information about HIV stigma, why it is an important problem and what impact it has for PLHA but also for our attempts to reduce the HIV/AIDS epidemic – if you are holding a workshop it is important that you understand the issues and have the correct information
- information on working with the media, working in a FBO and working in the workplace
- information on human rights and how to make them real, including practical information on how to bring cases to court
- fact sheets about HIV and stigma – you can photocopy these and use them in exercises or give them to people to take home with them. You can also use them in the workshop to reinforce the information you are providing
- contacts and resources – check whether you can contact any of these to give you more information or any other help to achieve your goal
- tools to run workshops – it is always useful to run exercises rather than just to provide information, because then people learn better through thinking for themselves and through their own experience, rather than just sitting and listening
- exercises to help workshop participants to explore stigma and also to look at HIV transmission. You can use these either to run a whole workshop or you can just choose individual exercises
- worksheets that you will need in the exercises
- information on facilitation skills to help you to facilitate the workshop exercises
- information to help you to prepare for the workshop
- sample curricula. You will need to decide what to include in your workshop and what to leave out. You may only have one day or a morning and you would need to decide the best way of using this time. The sample curricula will help you to do this
- information on how to monitor to make sure that you are achieving your objectives.
How adults learn

Training adults is different from teaching children. Adults have many life experiences from which you can draw and many of the answers are already within them. The facilitator’s role is to confirm people’s experiences and bring their knowledge to the surface, while also adding new ideas and information. When training adults, it is important to think about the following saying:

“I hear, I forget. I see, I remember. I do, I learn.”

This means that the best way for people to learn about something is to do it themselves and to link it to their own successes and failures. Learning is affected by a number of different factors, including gender dynamics. For example, men might expect to do all the talking while women sit and listen. Facilitators need to find positive ways to address this - for example, by women and men doing some parts of the training separately. Adults learn best from people with whom they feel at ease. So, where possible, it is good to have facilitators who share the same gender, age, ethnicity, etc. as the participants. Facilitators need to be able to create an enabling environment where learning is based on active participation and everyone building their knowledge together.

Experiential learning

Experiential learning means learning that is practical and based on real-life experiences. It is about learning from doing, rather than from theory.

Experiential learning can be seen as occurring in stages:

- **stage 1:** validating participants' existing experience and knowledge
- **stage 2:** adding new information and ideas
- **stage 3:** using activities and tools to get participants to contribute
- **stage 4:** summing up and agreeing on the key points arising from each Activity and identifying actions for change.

Helpful hint!

It is important to set the right mood and for the facilitators to encourage each other to be enthusiastic and creative.

To do this, you might like to start with a short, fun energiser to make everyone laugh and feel relaxed.

How groups work

We can think about what is happening among participants during the different stages of group development.

**Stage 1: Forming**

The participants are a set of individuals, rather than a group.

- The individuals want to establish their personal identity and to make an impression.
- Participation is limited while the individuals familiarise themselves with the setting, each other and the facilitator.
- The individuals begin to focus on the task at hand and to discuss its purpose.
- The group develops initial ground rules on which to base its future actions and decisions.

**Stage 2: Storming**

There are conflicts within the group and a lack of unity.

- Individuals break the initial ground rules on purpose.
- Individuals can become hostile towards each other and express their individuality by pursuing their personal agendas.
- Men might dominate discussions, with women being silenced or their contributions not acknowledged.
- The level of friction increases, rules are broken and arguments can happen.
- If successfully handled, this stage leads to developing new and more realistic objectives, procedures and norms.

**Stage 3: Norming**

Tensions are overcome and the group pulls together.

- Norms and practices are established.
- Individuals accept the group and each other’s uniqueness.
- Group allegiance develops and the members strive to maintain it. A group spirit develops and harmony becomes important.
Stage 4: Performing

This can only be reached by successfully completing the previous three stages.

- The group reaches full maturity and maximum productivity.
- Members take on flexible and functional roles so that they can fulfil the group's activities.
- The group's energy is channelled into its tasks.
- New insights and solutions begin to emerge.

Participatory training methods

Discussion is the core method – the activity through which participants reflect on their own experience, share with others, analyse issues and plan for action together. All of the sessions are built around discussion.

Presentations are kept to a minimum and are only used to summarise sessions.

Small groups are used to maximise participation in discussions. Some trainees may feel shy to talk in a large group but in a small group it may be easier to talk and participate. Small groups can also be used to do ‘task group’ work – different groups exploring different topics.

Buzz groups – two people sitting beside each other – are a trainer’s secret weapon! They help get instant participation. It is hard to remain silent in a group of two people!

Report backs are used to bring ideas together after small or buzz groups. Often ‘round robin’ reporting will be used – one new point from each group going round the circle. This ensures that all groups get a chance to contribute equally.

Cardstorming is a quick way of getting out ideas and getting everyone involved. Participants, working individually or in pairs, write single points on cards and tape them on the wall, creating a quick brainstorm of ideas. Once everyone is finished, the cards are organised into categories and discussed.

Rotational brainstorming is another form of brainstorming done in small groups. Participants break into groups and each group is given a starting topic. Each group records points on its topic on a flipchart and after 2–3 minutes moves to a new topic and adds points. During the exercise groups contribute ideas to all topics.

Worksheet includes pictures, which are to be used in different exercises. Some of the pictures show various aspects of stigma (picture codes) as a focus for discussion. Other pictures show different types of people (character cards) or events in the lives of PHLA (PLHA story or PLHA rights cards) and participants make up their own stories around them.

Stories and case studies are provided in many of the exercises as a way of describing how stigma appears in a real situation and providing a focus for discussion. In other exercises participants are asked to write their own stories about stigma.

Stop-start drama is a form of drama making combined with discussion. The drama ‘starts’ and then ‘stops’ for discussion (to analyse the issues) and then the drama ‘starts’ again.

Drama or role-plays are an alternative to stories. Participants act out the stories in the module or their own stories, or they act out their analysis of an issue as a way of reporting back what they have discussed. Drama helps to make things real.

Skill practice with feedback – the workshop process can be used to practise some of the skills needed to mobilise action against stigma: facilitating discussion and giving presentations. Some of the report-back sessions can be used to practise presentations – group reporters present their reports and then are given feedback on their performance.

Warm up games and songs – trainers are encouraged to use their own games and songs to break the ice, build group spirit, and create energy for sessions.

“We often do the same old things in our workshops – brainstorm and discuss, brainstorm and discuss – and participants get bored. What I liked about this approach is the methods kept changing. We had no time to be bored!”

Participant, Ethiopian Toolkit Workshop, May 2003
Some participatory facilitation methods in more detail

Small group work
Small groups involve 2-8 people and are the basic unit of participatory training. They:
• encourage meaningful discussions, including among shy participants, because the participants can test their ideas and learn from their peers
• bring together a diverse range of views as this helps with problem solving
• allow for personal growth, as long as participants are with others of similar interests, levels of experience, etc.
• are usually followed by a plenary to encourage further discussion.

Case studies
Case studies are descriptions of an incident or situation that has happened or could happen. They:
• are usually brief, of about 3-4 paragraphs in length
• are used to see what an issue means in real life and to analyse it
• can be fictional or based on facts taken from reports, etc.
• are followed by a discussion of the key points that have been highlighted.

Role-plays
Role-plays involve acting out real-life experiences. They:
• help participants to learn from and understand each other
• serve as good energisers
• are followed by a discussion about the key points that were highlighted
• are useful for improving participants’ interviewing techniques.

Helpful hint!
For role-plays it is important to:
• identify good actors for role-plays in advance and brief them on their roles
• if possible, prepare a stage and basic costumes and props for the role-play
• schedule role-plays after breaks in the workshop schedule - to allow time for the actors to get ready
• always de-role after a role-play – let the role-players express how they experienced the role-play, and acknowledge that they are no longer in role. This is particularly important if the role-play involved emotions.

VIPP
Visualisation in participatory programmes (VIPP) uses games, exercises, presentations, VIPP cards, etc., to enable participants to learn in a visual way. They:
• encourage critical thinking by raising questions about problems that people face
• empower people to act on their ideas and generate collective knowledge through interaction
• are followed by a discussion of the key points that have been highlighted.

Helpful hint!
VIPP cards are used for displaying participants’ ideas briefly. They can come in different colours, sizes and shapes. To use them well, facilitators should:
• use one card for each idea
• write no more than three lines per card
• use large writing and key words.

Energisers
Energisers:
• encourage team-building among the participants
• build trust between the participants and the facilitators
• maximise participants’ learning
• help facilitators identify resources within the group.

Helpful hint!
For small group activities it is important to:
• ensure that small group activities are prepared in advance, have clear instructions and are relevant to the issue in question
• make sure there is enough space so the groups do not distract each other
• ensure a balance among participants, for example in terms of age and sex.
Working with feelings

Many of the exercises in the Stigma Resource Pack involve working with feelings. An important component in anti-stigma training involves working with attitudes towards, experiences of, and beliefs about, traditionally taboo subjects like sex and death. To do this, many exercises are designed to help participants to express the feelings that often lie behind these attitudes.

An example of this is in the initial exercise of ‘naming the problem’. We ask participants to reflect on their own experiences of being stigmatised or of stigmatising. Experiences of being isolated, rejected, mocked inevitably invoke strong feelings. These feelings help participants to see how hurtful – and powerful – stigma can be.

As trainers, it is important to create a safe, non-threatening environment where feelings, fears and taboos can be discussed and explored openly. The following tips may help:

- Setting clear ground rules and expectations about confidentiality, listening and support are essential.
- Awareness of your own feelings and fears about the topics you are going to cover will also help you to feel more confident during the exercise (try out the exercises yourself).
- Participants are more likely to trust you if you can share your feelings openly. By doing this, you lead by example.
- Remember to always leave enough time for participants to share their feelings and help the group to create an atmosphere where participants know they will be listened to.
- Remember that no feeling is wrong – but some participants may find it difficult to accept certain feelings.
- Offer participants ‘time-out’ if they need to take a break.
- Feelings are a powerful tool – use them with the group to develop drama and role-plays, to build on stories, and as examples for the future.
- If there are any exercises you do not feel comfortable leading, find a co-trainer who can help out. If you have counselling skills, you are more likely to be confident in working with feelings.

The do's and don'ts of good facilitation

Do:

- Prepare and know your subject.
- Ensure that all participants have a role and can participate.
- Speak slowly and clearly.
- Use group work.
- Take account of barriers, such as language and literacy.
- Clarify key concepts.
- Keep focused.
- Guide the group’s discussions.
- Give summaries at the end of activities.
- Practice time management.
- Manage crises by being creative.

Don't:

- Dominate discussions.
- Be judgemental.
- Presume that you know what participants want to say.
- Panic if things don't go as planned.
- Think of yourself as the expert.
- Leave shy or difficult people out.
- Forget that HIV and AIDS are real and sensitive for many participants.
- Allow discussions to wander.
- Allow everyone to talk at once.
- Leave a discussion without a conclusion.
- Get too personally involved.
Knowledge, skills and attitudes of good facilitators

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<td></td>
<td>stigma</td>
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Checklist for co-facilitation

- Leave enough time to plan, design and prepare the workshop.
- Know your material well.
- Know each other well.
- Agree on cues to give each other if you are in trouble.
- Agree in advance how to support each other.
- Avoid interrupting when someone else is speaking.
- Decide how to deal with disagreements between yourselves.
- Agree on how to deal with controversial issues that come up between the participants.
- Decide where to sit during activities. Make sure that all of the facilitators are visible, but that the focus is only on one person at a time.
- After each session, talk about how the facilitation went.
- Be honest with each other about your strengths, weaknesses and problems.
Active listening and good questioning

Active listening encourages the open communication of ideas and feelings by making a participant feel not only heard, but also understood. It involves facilitators:

- paying attention to their body language – to physically show that they are listening
- listening to both what is said and how it is said in order to pick up on emotions as well as words
- if culturally acceptable, looking at the person who is speaking – to show that they are interested in and understand what the person is saying
- summarising what they have heard – to show that they have caught the main points.

Good questioning encourages people to go beyond simply providing information to sharing their views. It involves facilitators:

- asking open-ended rather than closed questions. For example: ‘What was the meeting like?’ rather than: ‘Did you go to the meeting?’
- asking probing questions. For example: ‘Could you explain what you meant about men not talking to their sons about sex?’
- asking clarifying questions. For example: ‘Is the problem that people lack condoms or that they lack good quality condoms?’
- asking questions about personal views and feelings. For example: ‘What do you feel about local health services for women?’

Why is planning important?

It is very important that there is proper planning for a workshop. Planning helps facilitators to ensure that each session meets its objectives. Preparation helps facilitators lead the training with more confidence, concentration and creativity.

Planning and preparation are particularly important for workshops on subjects that are controversial, emotional and/or new to the participants. Making basic arrangements in advance, for example about scheduling tea and lunch breaks and who is providing the tea and lunch, helps a workshop to run smoothly. It ensures that the learning process is continuous and not interrupted.

Making the workshop space comfortable and inviting – for example, by having a box of tissues available and removing the formal set-up of tables – is vital for setting the right kind of atmosphere.
Checklist: Before the workshop

Before the workshop, facilitators need to prepare themselves well, particularly in areas such as:

- **Administration.** Facilitators should ensure that the participants receive basic information about the workshop well in advance. For example:
  - Have the participants been sent an invitation letter, including details such as the dates, schedule, venue and objectives of the workshop?
  - Have the participants been told about any preparations that they need to make in advance? For example, do they need to bring information materials about their organisation to use in a presentation?

- **The room.** Facilitators should visit the room in advance and check the following:
  - Is there enough space to display materials and VIPP cards?
  - Are there enough flipcharts, masking tape, markers, etc.? Is there a table on which you can put your materials?
  - Is the room arranged how you want it? For example, are the chairs arranged so that participants can see each other and is there enough space for people to work in small groups?

- **The participants.** Facilitators need to find out as much as they can about who will be taking part in the workshop. This includes the following:
  - Will people know each other?
  - What is each participant’s background, gender, level of education, areas of expertise and knowledge about the subject of the workshop?
  - What are the aims and activities of the participants’ organisations? Does their work already cover the subject of the workshop or will it be introducing it to them for the first time?
  - How will you adapt the workshop’s activities and discussions to suit the participants’ existing experience and knowledge?

- **The training manual.** If there is a training manual, facilitators need to read it carefully in advance. This is in order to establish the following:
  - Do we understand all of the activities? What can we use straight from the manual and what do we need to adapt?
  - How can we make the manual as easy as possible to use? For example, do we need to put markers in key activities, so that we can find them quickly?
  - What questions or problems are likely to arise that aren’t covered by the manual? How are we going to deal with them?

- **The co-facilitators.** Facilitators should meet their other team members and resource people, in order to know:
  - how to divide the facilitation roles and responsibilities before and during the workshop
  - how to make sure the workshop flows
  - how to use our time most productively.

If possible, the workshop room should have space for the participants to sit in a circle or ‘U’ shape, as well as some round tables, each with 5-6 chairs. The round tables help participants to move quickly into small workgroups and encourages them to interact with each other and to ‘bond’. It is a practical way to ensure that the learning process moves from discussing concepts to applying them to participants’ practical work.
In particular, facilitators need to be committed to:

- using the type of participatory methods outlined in this manual/resource pack

- addressing the barriers to participation. Facilitators need to be aware of what helps and hinders participation by different types of people. This includes identifying which barriers are:
  - individual factors, such as a person’s level of shyness
  - systematic factors, such as whether a person can speak the language or has a different level of experience
  - gender inequality factors. Different men and women act differently in groups. For example, while some men tend to dominate, some women might be quiet and feel unheard. Sometimes, this can be due to the individuals concerned. At other times, it can be due to the different roles society places on men and women.

During the workshop, facilitators need to be flexible and be able to deal with challenges that might arise. Every group of participants is different. So, even if you have prepared your activities carefully, you may need to alter them on the spot. For example, you might find that a specific issue needs more explanation, discussion or case studies.

Developing objectives for your workshop

Develop a set of objectives for your participatory training workshop. Ensure that your objectives are:

- clear and simple
- realistic
- appropriate for the subject matter
- appropriate for the participants.

Example of objectives for a participatory training workshop

The objectives for a regional workshop on mainstreaming gender into HIV and AIDS work by the Tanzania Gender Networking Programme (TGNP) were that, by the end of the training, the participants would have:

- explained and applied key gender concepts relating to policy issues around HIV and AIDS prevention and intervention
- applied and critiqued participatory methodology in addressing HIV and AIDS
- developed a conceptual and analytical framework for gender policy and HIV and AIDS
- identified gender constraints, gaps and opportunities in existing HIV and AIDS programmes
- shared information and networking experiences on gender policy and HIV and AIDS in the sub-region.
Preparing a work schedule

Within the facilitation team, draw up a basic schedule for your training workshop that shows:

- how many days you have available
- how many hours you have available each day
- any general things that have to be included in the schedule, such as an opening ceremony or provisions for tea breaks and lunch breaks.

Review the contents that you want to include in your training workshop and consider:

- What do you know about the existing knowledge, skills and experience of the participants?
- What subjects and activities are your priorities?
- How much time is needed for those subjects and activities, both individually and as a whole?

Fill in the schedule for your training workshop by:

- deciding on a logical order for the subjects and activities
- allocating an amount of time to each subject and activity
- identifying within the facilitation team who will be responsible for each activity.

Preparing to evaluate the workshop

Identify the information about the workshop:

- which you as facilitators need to gain
- which will be the most relevant and useful, considering the participants
- what will be the most appropriate, considering the subject of the workshop.

Decide what methods you will use to evaluate your workshop.

Identify who within the facilitation team will take the lead on preparing and carrying out the evaluation.

Ways of evaluating a workshop

1. Daily and participatory

   With this method:

   - Each day, the trainer asks the groups to appoint someone to be the ‘eyes and ears’ for the day’s activities. The participants feed their comments to this person who then provides a short summary at the end of the day.
   - Where possible, the facilitators take action on the comments from the participants. Where this is not possible, the facilitators explain why.
   - This draws attention to existing or developing problems. It also tests the extent to which participants have absorbed the day’s learning.

2. Daily, and by each participant

   With this method:

   - Participants fill out an anonymous evaluation form at the end of each day. This enables them to comment on the parts and activities honestly and personally.
   - If, however, you are running a five-day workshop, it may be more useful to provide an evaluation form at the end of each part or couple of parts. This is particularly useful if daily and participatory evaluations are also taking place.

Where possible, have at least two facilitators for each activity. This is so that you can work as a team but have different roles. For example, while one facilitator is leading a discussion, the other can write the key points on a flipchart.
3. Self-evaluation

With this method:

- At the beginning of the workshop, participants should be asked to identify the gaps in their existing knowledge and what they want to learn during the workshop.
- At the end of the workshop, participants should be supported in developing personal action plans. This is so they can apply what they have learned to their own organisation and work.

4. Evaluation by facilitators and organisers

With this method:

- Those who are facilitating and organising the workshop are involved in ongoing evaluation.
- This might involve having an evaluation committee that meets at the end of each day and includes a representative of the participants. The committee could reflect on the feedback from the participants, discuss how the workshop is going and identify any changes that need to be made.

Whatever evaluation methods are used, a brief report should be produced that summarises the feedback from the participants and facilitators. This should be made available to the participants, plus any other relevant groups, such as donors.

Starting a participatory learning workshop

Within the facilitation team, draw up a basic schedule for your training workshop that shows:

- how many days you have available
- how many hours you have available each day
- any general things that have to be included in the schedule, such as an opening ceremony or provisions for tea breaks and lunch breaks.

Review the contents that you want to include in your training workshop and consider:

- What do you know about the existing knowledge, skills and experience of the participants?
- What subjects and activities are your priorities?
- How much time is needed for those subjects and activities, both individually and as a whole?

Fill in the schedule for your training workshop by:

- deciding on a logical order for the subjects and activities
- allocating an amount of time to each subject and activity
- identifying within the facilitation team who will be responsible for each activity.
The majority of people living with HIV interviewed in the Siyam’kela Project emphasized how valuable and important counselling, information, and support groups (both formal and informal) had been in their journey to overcoming the emotional upheaval of discovering their positive status, as well as in starting to live positively. Many stories were shared of how people had not received any pre- or post-test counselling for their HIV test. As a result they had been uninformed about the disease and relied on popular knowledge and myths, and on ill-equipped medical practitioners for guidance. Countless HIV-positive people were informed upon receiving their results that they would die within a couple of days. Only a handful could share positive experiences of proper counselling.

**Individual counselling**

Many people living with HIV need to be assisted to process internal stigma in individual counselling and in support groups so that they are good role models for others and are able to stand up to stigma when they experience it. Unpublished research conducted at a large South African hospital found, for example, that disclosure was a process in which individuals first had to come to terms with their new status and understand fully its implications, before they could be in a position to tell others about it. While the study found that many of the participants seemed to be getting support at the household level, this was often limited and conditional, and often dependent on the assertiveness, confidence, and positive role modelling from the person living with HIV. This often required extensive support from counsellors.

**Personal development**

People living with HIV who are given opportunities for self-development can learn to overcome internal stigma. Many community-based organisations train their members with leadership skills to get involved in community development. The Siyam’kela Project noted the power of media to shape perceptions and attitudes towards HIV and has developed empowerment workshops for people living with HIV to improve their skills in working with media practitioners. All the people living with HIV who had developed confidence in working with the media showed similar traits: they had dealt with disclosure issues well before working with the media; they had confronted their internal stigma; they prepared well for a media interview; they established a strong personal support base; they knew in advance what kind of message they wished to convey; they challenged the media practitioner on stigma; they encouraged practitioners to move beyond simplistic stories to more complex ones; they asserted their right to see stories prior to publication; they actively sought to develop skills in working with media; and they shared their skills and successes with other people living with HIV. Similarly, a Mexican stigma project produced a photojournal profiling 10 people living with HIV to help counteract stereotypes and provide the media with positive images of those affected by the epidemic.

Recognising the need for internal stigma work with people living with HIV, Siyam’kela has developed a one-day workshop aimed at HIV-positive people which focuses specifically on internal stigma. Themes covered in this workshop include definitions of stigma, personal experiences of stigma, rating one’s own internal stigma, strategies to challenge internal stigma, media interaction skills, personal effectiveness and stigma advocacy.

Economic independence can engender in a person living with HIV a sense of self-worth. Reduced reliance on partners and families can diminish the economic burden that may have come from caring for someone living with HIV or AIDS. This in turn can reduce potential hostility towards the person living with HIV, positively affect stigma and thus reduce internal stigma. The provision of antiretroviral treatment (ART) is a critical aspect of this: treatment promotes wellness and an ability to work and contribute to household income. On a broader level, increased economic stability amongst the general population of a country will have an impact on diminishing HIV/AIDS-related stigma.
Support groups

Support groups which are facilitated for and by PLHA themselves send a clear message of competence and independence to group members and their communities. As one of the consequences of internal stigma is a withdrawal from social and health services, these support groups can provide a safe space for support, exploration, and growth and, in turn, people living with HIV can achieve a level of confidence to assert their rights in various settings.

Support groups help with personal growth, self-esteem and self-worth. Support groups facilitate a sharing of experiences, convey information, and give practical advice on a range of HIV wellness and treatment options. They assist with social confidence, improve an individual’s social capital by helping them to be a part of organisations, feel a sense of connection to their community, believe that they can impact social processes, and develop a sense of trust in social institutions and authorities.

Support groups for those experiencing secondary stigma are also an important intervention to assist those close to people living with HIV to process the internal stigma they may be experiencing. Families need assistance to process their thoughts and feelings about their HIV-positive family members. This may include family counselling and support group work. It would involve information giving, demystifying beliefs, clarifying values, and accessing resources to lessen the burden on the family.

Information on running support groups can be obtained from HIVSA at the Chris Hani Baragwanath Hospital (www.hivsa.co.za).

3.10 Measuring our work

Many people believe that it is important to assess the level and nature of stigma before attempting interventions to reduce stigma. This allows one to know how big the problem is and also pinpoints the areas which need to be addressed. So assessing stigma is a very useful task to undertake.

Assessing stigma provides information on the aspects which can be measured to get an idea of the level and nature of stigma in a particular group of people. From this one would be able to draw up a questionnaire to assess stigma.

This module provides information on the indicators of stigma developed by the Siyam’kela Project. Using these indicators can provide information on the level and form of stigma within a particular group.

The indicators are presented according to themes. The 12 themes are divided across two categories, namely internal and external stigma, and include:

**External stigma**
- Avoidance
- Rejection
- Moral judgement
- Stigma by association
- Unwillingness to invest in PLHA
- Discrimination
- Abuse

**Internal stigma**
- Self-exclusion from services and opportunities
- Perception of self
- Social withdrawal
- Overcompensation
- Fear of disclosure

The indicators for each theme are presented in a table (see example below). The table relates the indicators to the relevant fieldwork finding, names the indicators, provides important definitions, notes how the indicators may relate to pre-existing stigma, suggests how the indicators may be verified in different settings, and lists conditions for use of the indicators. It is important to read through the example below to understand how the indicators were arrived at and how they can be used effectively. The reader will also note that some indicators can be used in settings where there is a significant number of PLHA who have disclosed their HIV status and some can be used when no PLHA have disclosed.
## Need to know more?

See Tool 4.4 Indicators for Stigma – a summary

### 3. Intervention options

#### Theme

The overall finding of the study is presented together with some illustrative quotes taken from the fieldwork.

#### Indicators

This block presents the relevant indicator/s. An effort has been made to make the indicators general and applicable to various settings, including workplace, faith-based organisations, and other social settings, such as recreational groups.

**Two sets of indicators** are presented. The first set requires a significant number of openly disclosed PLHA within an organisation, while the second set does not require this condition. The second set appears in the lighter shaded block.

All the indicators listed below measure how high the levels of stigma are within a setting. Only indicators 12.1 and 12.2 measure low levels of stigma within an environment, namely:

- **12.1 Number of PLHA who have disclosed their HIV-positive status**
- **12.2 Number of PLHA who are willing to publicly disclose their status to the media**

#### Definitions

It is up to the user to specifically define the indicators so as to ensure that they apply within their own context. Terms used in the indicators have been defined to guide the user when applying the indicators to a specific project. The list of examples, however, is not comprehensive since it is limited to reflect the findings of the Siyam’kela study.

Stigma operates in relation to difference and can, in principle, function in relation to any “key axes of structural inequality”, such as gender, class, race, and sexuality. HIV/AIDS stigma has been found to function in relation to **pre-existing** and/or independent forms of stigma and exclusion, which heightens its impact. HIV/AIDS stigma can have especially negative responses when it is based on pre-existing stigma and discrimination.

For all themes it is important to remember that some groups may experience HIV/AIDS stigma differently based on, for example, their gender, age, sexual orientation and geographic location. Even though the study did not always find differences in experience, the main purpose of this block is to **remind the reader of the possibility of pre-existing stigma** and of its possible effects on stigma mitigation. It is therefore important to measure these possible differences when assessing the progress of a stigma mitigation process. All of the indicators presented below can be made more specific so that they measure these different experiences.

For example, the indicator “**Number of PLHA who report cases of others not sharing objects with them**” can be re-written as: “**Number of female PLHA who report cases of others not wanting to share objects with them**”. Other categories can similarly be included.

#### Means of verification

The possible means of confirming the indicator are presented, listing the tools and the denominators. Denominator refers to the total sample size.

#### Conditions

The necessary conditions for using the indicator are listed in this block.
### Theme: Avoidance

**Finding**

PLHA report being avoided by others, often because of a fear of casual transmission of HIV or because of a perception of PLHA as immoral and dirty. Avoidance may take the form of not wanting to share items or spend time with PLHA.

“They are nice to you but they keep their distance. You don’t really have many friends.”

Female person living with HIV/AIDS

“You sit down [in church] and they all get up and go sit somewhere else.”

Male person living with HIV/AIDS

“Many a times I have had people shout at me saying, ‘Don’t come near me, I am scared of you’.”

Male person living with HIV/AIDS

**Indicators**

| 1.1 | Number of PLHA who report cases of others not sharing objects with them |
| 1.2 | Number of PLHA who report cases of others who distance themselves from them socially |
| 1.3 | Number of PLHA who report an experience where they feel as if others reduce them to the HIV virus, and no longer see them as a whole person |
| 1.4 | Number of PLHA who report cases of others who distance themselves from them physically |
| 1.5 | Number of PLHA who report cases of others gossiping behind their backs |
| 1.6 | Number of people who would not share objects with PLHA |
| 1.7 | Number of people who would distance themselves socially from PLHA |
| 1.8 | Number of people who would distance themselves physically from PLHA |
| 1.9 | Number of reports of people distancing themselves from PLHA, and/or their affected friends and family |

**Definitions**

- Objects may include utensils, facilities, equipment and furniture.
- Social distancing may include spending less time with PLHA than before they learnt of their HIV-positive status and/or excluding PLHA from social events or conversations.
- Reducing to the HIV virus may include individuals no longer recognising other aspects of a PLHA’s life.
- Physical distancing may include no longer wanting to be touched by a PLHA, and keeping greater distance between themselves and PLHA than before they learnt of their HIV-positive status.
- Organisation/social setting refers to any social structure, for example, workplace, faith groups, recreational groups, interest groups and family.

**Relationship to pre-existing stigma**

- Race:
  
  “We still have the division in South Africa that AIDS is a black thing, so it won’t come to me. You know, in the white community we find ourselves in a difficult situation of not accepting, and of thinking that this is a black thing.”

  HIV/AIDS co-ordinator

- Gender
- Age
- Sexuality
- Geographic region

**Means of verification**

- Survey with PLHA: sample size as the denominator
- Survey with people within the organisation or social setting using a social distance scale

**Conditions**

- PLHA need to have openly disclosed within the organisation or social setting.
- Respondents are honest in sharing their perceptions and feelings on the sensitive topic of stigma.
### Theme 2: rejection

#### Finding

Many PLHA have suffered rejection from their spouses, families, friends and colleagues due to the perception that PLHA deserve the illness or that HIV can be transmitted through casual contact.

> “You experience it [rejection], especially at home. When you tell your family that you are [HIV] positive they start to chase you away. Like they did to me. They said that I must leave, and must stay away.”

*Male person living with HIV/AIDS*

> “He told me he loved me and I asked him if he’s sure and he said yes. Then I tell him I’m HIV-positive and he just went quiet for fifteen minutes. He doesn’t want to be associated with me.”

*Female person living with HIV/AIDS*

#### Indicators

- 2.1 Number of PLHA who have been abandoned by significant people in their lives
- 2.2 Number of PLHA who were pressurised to leave their organisation/social setting after publicly disclosing their status
- 2.3 Number of PLHA who were pressurised to leave their place of residence
- 2.4 Number of people who would abandon significant people in their lives if they were to find out that they were HIV positive
- 2.5 Number of people who feel that PLHA should not be welcomed within their organisation/social setting
- 2.6 Number of people who feel that PLHA would not be welcomed in their homes

#### Definitions

- Significant people may include a spouse/partner, family members, friends and colleagues.
- Organisation/social setting refers to any social structure and setting, including for example workplaces, faith groups and recreational groups.

#### Relationship to pre-existing stigma

- Gender:
  > “She disclosed to her partner when she was three months pregnant and he didn’t say anything. He then left and never came back again. When he went away he never came to visit and even now the child is sick he doesn’t come to check on the baby in the hospital.”

*Female person living with HIV/AIDS*

- Race
- Age
- Sexuality
- Geographic region

#### Means of verification

- Survey with PLHA: Sample size as the denominator.
- Survey with people within an organisation/social setting using a social distance scale

#### Conditions

- Existence of sufficient number of openly disclosed PLHA
- Respondents are honest in sharing their perceptions and feelings on the sensitive topic of stigma
### Theme 3: moral judgement

**Finding**

Moral judgement involves viewing PLHA as either ‘guilty’ or ‘innocent’ in terms of how they contracted HIV. Such thinking allocates blame and allows people to distance themselves from PLHA. This ‘othering perception’ dismisses PLHA as ‘promiscuous’, ‘sinful’ or ‘irresponsible’ and allows discrimination to appear justified.

Some organisations struggle to find appropriate non-judgemental prevention messages in relation to HIV/AIDS.

> “If you contracted HIV/AIDS it must have been through sex. It must have been unlawful sex. Therefore you are a sinner and it’s a punishment from God.”
> Faith leader

> “People look at you and they start thinking, she’s been sleeping around.”
> Female person living with HIV/AIDS

**Indicators**

- 3.1 Number of PLHA who report cases of the others using the concept of blame to inform their response to them
- 3.2 Number of PLHA who report cases of others who present HIV/AIDS in terms of a moral judgement
- 3.3 Number of people who use the concept of blame to inform their response to PLHA
- 3.4 Number of people who present HIV/AIDS in terms of a moral judgement

**Definitions**

- Concept of blame may include the perception of PLHA as innocent, guilty or deserving, based on their behaviour and perceived responsibility.
- Moral judgement is similar to the concept of blame, as it labels (according to perceived set of norms) PLHA as immoral based on a religious belief or on values.
- Organisation refers to any social structure and setting, including for example workplace, faith groups, and recreational groups.

**Relationship to pre-existing stigma**

- Gender:
  > “I still have to find a woman who will openly say ‘I messed around’. They all became infected through their partners innocently. I find it difficult to believe sometimes.”
  > Male person living with HIV/AIDS

  > “They say people who have HIV are prostitutes only.”
  > Female person living with HIV/AIDS

  > “I think that especially a female, once that person has found out that she is HIV positive and then she does not have any offspring but she decides to have a child, knowing that she is HIV positive, [she is then] also labelled as guilty because of the possibility that the offspring might get the virus.”
  > Female person living with HIV/AIDS

- Race
- Age
- Sexuality
### Theme 4: stigma by association

#### Finding

As a result of the silence surrounding HIV/AIDS and fear of casual transmission, a culture of suspicion has developed whereby some people try to identify possible PLHA through associations.

> “If we see that you are losing weight, whether you are exercising or whatever, we just assume that you have AIDS.”
>  
> Junior staff member

> “Sometimes I wonder if people don’t think we are all [HIV] positive because we work in this field.”
>  
> HIV/AIDS co-ordinator

#### Indicators

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<tr>
<td>4.1</td>
<td>Number of PLHA who report cases of others who stigmatise those who are associated with them</td>
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<tr>
<td>4.2</td>
<td>Number of people within an organisation/social setting who stigmatise individuals based on associations related to HIV/AIDS</td>
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<tr>
<td>4.3</td>
<td>Number of people who report having been stigmatised by others as a result of their association with HIV/AIDS</td>
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#### Definitions

Associations may include:

- medical conditions (such as TB, pneumonia, weight loss, skin diseases, no cause of death specified)
- working in the field of HIV/AIDS, campaigning for HIV/AIDS issues
- befriended by or related to a PLHA
- part of a group vulnerable to HIV infection, for example a commercial sex worker, migrant worker or drug user.

#### Relationship to pre-existing stigma

- Gender
- Race
- Age
- Sexuality
- Geographic region

#### Means of verification

- Survey with PLHA
- Reports from care workers, affected family and friends
- Survey of members of organisation/social setting: Sample size as denominator
- Focus group with members of the organisation or social setting

#### Conditions

- Existence of sufficient number of openly disclosed PLHA
- Respondents are honest in sharing their perceptions and feelings on the sensitive topic of stigma
### Theme 5: unwillingness to invest in PLHA

**Finding**

In some cases people claimed that they would not disclose their HIV status if they learnt that they were HIV positive for fear that there would be career-limiting consequences within their organisations. This is based on a commonly held belief that investing in PLHA is a waste since people assume that PLHA are not productive and will die very soon.

“Because obviously the minute you disclose you will lose everything. They won’t bother training you anymore.”

HIV/AIDS co-ordinator

“There is also the perception that if you disclose you are not going to be considered for senior positions and that your supervisor is not going to invest in you. Why should the department invest in you, spend R30 000 on you if they are only going to get 5 years out of you?”

Senior manager

**Indicators**

| 5.1 | Number of PLHA who are marginalised within their organisations after having disclosed their HIV status, despite adequately performing their assigned roles |
| 5.2 | Number of leaders within an organisation who would not consider investing in openly disclosed PLHA |

**Definitions**

- Marginalised is understood as not receiving training and development, promotion or given less responsibility than before disclosing one’s HIV status.
- Investing may include training or ongoing formation, promotion or giving a person more responsibility.
- Organisation in this particular theme of indicators, refers to formal social structures such as workplace settings and faith groups.

**Relationship to pre-existing stigma**

- Race
- Age
- Sexuality
- Geographic region

**Means of verification**

- Survey with PLHA: Sample size as denominator
- Focus group with PLHA
- HR records (training records, job descriptions): Number of trainees/members of organisation as denominator
- Survey with people within the organisation: Sample size as denominator

**Conditions**

- Existence of sufficient numbers of openly disclosed PLHA
- Existence of HR and training records within organisations
- Respondents are honest in sharing their perceptions and feelings on the sensitive topic of stigma
### Theme 6: discrimination

#### Finding

Some service providers perceive providing services and opportunities to PLHA as a waste of resources because HIV/AIDS is not understood as a chronic disease. Similarly, PLHA have experienced discrimination within their organisations.

“When I go to the police to ask for help they tell me they are tired of HIV/AIDS. And the magistrate also said he doesn’t accept cases of HIV/AIDS.”

Female person living with HIV/AIDS

#### Indicators

<table>
<thead>
<tr>
<th>Indicator</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>6.1</td>
<td>Number of PLHA who have been denied services because of their HIV-positive status</td>
</tr>
<tr>
<td>6.2</td>
<td>Number of people who would deny services to an HIV-positive person</td>
</tr>
<tr>
<td>6.3</td>
<td>Number of reported cases of HIV/AIDS stigma and discrimination in the organisation/social setting</td>
</tr>
</tbody>
</table>

#### Definitions

- **Denied services** includes, among other services, emergency services, financial institutions, medical practitioners and insurance companies.
- **Reported cases** implies the use of formally constituted channels of complaint.
- **Organisation/social setting** refers to any social structure and setting, including for example workplace, faith groups, and recreational groups.

#### Relationship to pre-existing stigma

- Gender
- Race
- Age
- Sexuality
- Geographic region

#### Means of verification

- Survey with PLHA: Sample size as denominator
- Focus group with PLHA
- Records from organisations dealing with workplace discrimination and unfair labour practices
- Survey with people providing the services
- HR records within organisations: Number of all HR-reported cases as denominator
- Records of organisations that specialise in HIV/AIDS law. For example in South Africa, the AIDS Law Project and the AIDS Legal Network

#### Conditions

- Existence of a sufficient numbers of openly disclosed PLHA
- Existence of HIV/AIDS policies and formally constituted channels of complaints within organisations
- Implementation of a monitoring system
- Respondents are honest in sharing their perceptions and feelings on the sensitive topic of stigma
### Theme 7: Abuse

#### Finding

Some PLHA have experienced abuse by others because they were perceived as immoral or as a threat to the community.

- “Twice I was threatened with my life where people openly told me: If you don’t leave now we will kill you.”
  - Male person living with HIV/AIDS
- “When you go back to your man and disclose, tell him you are HIV-positive, he runs away or he beats you.”
  - Female person living with HIV/AIDS
- “In your social life people call you names ...you’re a flipping bad guy, or you’re an addict or say I never knew he was in the closet, things like that.”
  - Male person living with HIV/AIDS

#### Indicators

1. Number of PLHA who have been verbally abused as a result of their HIV status
2. Number of PLHA who have been physically abused as a result of their HIV status
3. Number of people who think that verbally abuse of PLHA is justified
4. Number of people who think that physical abuse of PLHA is justified

#### Definitions

- Verbally abused includes name-calling, insults and threats.
- Physically attacked includes cases of violence by others and even murder.

#### Relationship to pre-existing stigma

- Gender:
  - “I mean for a woman it is difficult to negotiate the use of a condom. Maybe she’s my partner and we start negotiating the use of a condom. The response is that I am going to beat the hell out of her and she may admit that she doesn’t trust me.”
  - Male person living with HIV/AIDS
- Gender, race, geographic location:
  - “When you go to rural areas I think women are more vulnerable in terms that in some cultures like Venda, Zulu, Xhosa and the like, you find that women don’t have the power to have a say when it comes to sexual intercourse […], especially when they are married. Whether the man is HIV positive or not, women just have to submit and give the man what he wants.”
  - Female person living with HIV/AIDS
- Age
- Sexuality

#### Means of verification

- Survey of PLHA: Sample size as denominator using the ‘conflict tactic’ scale
- Focus group with PLHA
- Records from organisations dealing with workplace discrimination and unfair labour practices
- Survey of people within organisation/social setting

#### Conditions

- Existence of sufficient number of openly disclosed PLHA
- Respondents are honest in sharing their perceptions and feelings on the sensitive topic of stigma
### Theme & self-exclusion from services and opportunities

#### Finding
Some PLHA have chosen not to seek out services or opportunities associated with HIV/AIDS because of their fear of stigmatisation.

> “Even if there is an offer of a job, I would not apply. It is hard because you think that they will draw blood or look at your urine and see that something is wrong.”

Male person living with HIV/AIDS

#### Indicators
| 8.1 | Number of PLHA who choose not to access existing support services |
| 8.2 | Number of PLHA who choose not to apply for a job because of their fear of being exposed as HIV positive |

#### Definitions
Existing services may include support groups, material assistance programmes, clinics.

#### Relationship to pre-existing stigma
- Gender
- Race
- Age
- Sexuality
- Geographic region

#### Means of verification
- Survey of PLHA: Sample size as denominator
- Service records: Number of clients as denominator

#### Conditions
- Existence of a sufficient number of openly disclosed PLHA
## Theme 9: perception of self

**Finding**
PLHA seem to be more vulnerable to internalising stigma after being diagnosed with HIV when they have poor coping mechanisms, are within a non-supportive environment, and/or have past experience of external stigma and discrimination.

*I wouldn’t feel comfortable … because I was feeling that I disappointed those people.*
Female person living with HIV/AIDS

*First, I apologised to the church and asked them to take me as I am. And I asked them to give me a second chance to prove myself.*
Female person living with HIV/AIDS

<table>
<thead>
<tr>
<th>Indicators</th>
<th>9.1 Number of PLHA who have low self-esteem as a result of their HIV-positive status</th>
</tr>
</thead>
<tbody>
<tr>
<td>Definitions</td>
<td>- Low self-esteem may include perceiving yourself as less valuable than those who are not living with HIV/AIDS, as a disappointment to others, as guilty and immoral, or as a threat to others’ health.</td>
</tr>
</tbody>
</table>
| Relationship to pre-existing stigma | - Gender  
- Race  
- Age  
- Sexuality  
- Geographic region |
| Means of verification | - Survey with PLHA: Sample size as the denominator  
- Focus group with PLHA  
- Application of self concept and depression scales with PLHA |
| Conditions | - Existence of a sufficient number of openly disclosed PLHA |
3. Intervention options

Theme 10: social withdrawal

<table>
<thead>
<tr>
<th>Finding</th>
<th>PLHA may perceive the need to withdraw socially in order to protect themselves (and/or their family and friends) from stigmatisation and discrimination.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>“HIV has changed something in me. It has changed the way I conduct myself in front of people. I cannot be comfortable with my family because they … look at me differently. So then I also changed and became a loner. I decided to hide myself.”</td>
</tr>
<tr>
<td></td>
<td>Male person living with HIV/AIDS</td>
</tr>
<tr>
<td></td>
<td>“Although I’ve accepted the virus myself, the thing is I don’t want anyone next to me.”</td>
</tr>
<tr>
<td></td>
<td>Male person living with HIV/AIDS</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Indicators</th>
<th>10.1 Number of PLHA who have fewer interactions with people than before they learnt of their HIV status</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>10.2 Number of PLHA who choose not to have intimate relationships</td>
</tr>
<tr>
<td></td>
<td>10.3 Number of PLHA who have fewer interactions with HIV-negative people</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Definitions</th>
<th>Fewer interactions could be defined in terms of number of people (close friends and associates) spoken to for a specified time period.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Intimate relationships may refer to a close relationship between two people that may include a sexual relationship.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Relationship to pre-existing stigma</th>
<th>Gender</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Race</td>
</tr>
<tr>
<td></td>
<td>Age</td>
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<tr>
<td></td>
<td>Sexuality</td>
</tr>
<tr>
<td></td>
<td>Geographic region</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Means of verification</th>
<th>Survey with PLHA: Sample size as the denominator</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Focus group with PLHA</td>
</tr>
</tbody>
</table>

| Conditions | Existence of a sufficient number of openly disclosed PLHA |
## Theme 1: overcompensation

### Finding
PLHA may perceive the need to overcompensate in terms of their behaviour in order to prove and to protect themselves from stigmatisation and discrimination.

“For me, I would say that earlier I thought I was doing what I thought was godly. I was doing my best to serve God. But when I found out that I was [HIV] positive I said no, I think it was not enough.”

Female person living with HIV/AIDS

### Indicators
- Number of self-reports from PLHA who believe they contribute more than people who are not living with HIV/AIDS as a means of proving themselves

### Definitions
11.1 Contributing more may include working harder or making more of an effort than people who are not living with HIV/AIDS.

### Relationship to pre-existing stigma
- Gender
- Race
- Age
- Sexuality
- Geographic region

### Means of verification
- Survey with PLHA: Sample size as the denominator
- Focus group with PLHA
- Survey of leaders or family members of openly disclosed PLHA
- Reports from managers who employ PLHA

### Conditions
- Existence of sufficient number of openly disclosed PLHA
### Theme 12: fear of disclosure

#### Finding
Disclosure of an HIV-positive status is a very difficult challenge as PLHA are concerned about the consequences for themselves and those close to them. As a result many PLHA do not disclose to others the news of their HIV status.

> “Some PLHA just cannot find it in themselves to disclose because of the stigma. They just have so much to lose - the respect of their community and family. Their friends will reject them. So they live in silence. It is an enormous burden to be scared of stigma.”
> Female person living with HIV/AIDS

> “Now the very same issues that you as the [HIV]-infected person has to deal with, your partner and child go through the very same thing.”
> Male person living with HIV/AIDS

#### Indicators

1. Number of PLHA who have disclosed their status
2. Number of PLHA who are willing to publicly disclose their status to the media
3. Number of people who would not disclose their HIV-positive status due to fear of stigmatisation

#### Definitions
- Disclosure includes different levels of disclosure associated with varying degrees of risk and include, among others, disclosure to sexual partner, family, children, friends and the public.

#### Relationship to pre-existing stigma
- Gender

> “You fear that I’m going to lose friends, people thinking that maybe I’m just a prostitute. That kind of thing. So that’s why it’s difficult sometimes to tell someone your [HIV-positive] status.”
> Female person living with HIV/AIDS

- Race
- Age
- Sexuality
- Geographic region

#### Means of verification
- Focus groups with PLHA
- Survey with PLHA: Sample size as denominator
- Survey with people within organisation/social setting: Sample size as denominator
- Frequency count of media reports of people disclosing

#### Conditions
- Existence of sufficient number of openly disclosed PLHA
- Respondents are honest in sharing their perceptions and feelings on the sensitive topic of stigma
Section 4

4. Tools to support interventions

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| TOOL 4.2 | HUMAN RIGHTS VIOLATIONS – LAYING A CHARGE | 80 |
| TOOL 4.3 | THE ADVOCACY PLAN | 81 |
| TOOL 4.4 | INDICATORS FOR STIGMA: A SUMMARY | 82 |
Tools to support interventions

Interviewing techniques

Interviewing is more than just asking questions about a particular theme. It is also about making a person feel comfortable to disclose his/her story or problems. This is only done by building rapport with the person being interviewed, and leaving all preconceived notions and judgemental attitudes behind. To get all the information that is required, the interviewer may need to think of alternative ways to ask the same question. The interviewer should also observe the surroundings, especially if the interview is taking place at the home of the interviewee, which may provide information that requires follow-up.

A very important part of the interview, which can provide a great deal of information, involves listening. Active listening is a skill and involves paying attention and picking up on verbal and non-verbal cues. A good interviewer will be flexible and change the questions and the direction of the interview, depending on what is emerging from the interview.

Taking a statement

A statement is a record of the story. It outlines what happened, when, how and to whom. It is always best to take a statement from the person who was directly involved in the incident in question. It is a good idea to take detailed notes while meeting with the person as soon as possible after the incident, when it is still fresh in his/her mind. Important information to include in a statement is the personal details of the person, the description of the problem and the advice given to the person.

Personal details

It is important to get as many personal details as possible when speaking to someone. This may be easier if the interviewer explains that this information is confidential and is only for the record. Important details may include:

- full names – ensure that names are spelled correctly
- address – ask if post can be delivered to this address
- contact numbers and the best time to call
- identity number
- employer’s name, address and telephone number, if relevant
- age or date of birth
- work details
- number of children and their ages
- marital status, and whether married by custom and/or in community of property or out of community of property
- doctor’s name and address, if necessary
- hospital care number, if necessary, and
- any other relevant details.

Description of the problem

It is important to write down as much detail as possible about the problem or the incident. Listen carefully to what the person is saying. It is a good idea to listen and then ask questions to clarify what the person is saying. Try not to interrupt or to make assumptions without hearing the complete story. It is helpful to write down the details in the correct order in which they occurred.
Tips for giving advice

Before giving advice, it is useful to ask the person what he/she wants to happen. It may be that what the person wants to happen is not possible. If this is the case, explain clearly to the person that it cannot happen, why it is not possible, and any possible alternative action that could be taken. If the person does not have a reasonable case, or if it does not seem that there will be any recourse available, it is important to be honest and direct, while at the same time explaining that this does not mean that the incident did not happen or was not important. This will validate the person whose rights have been violated.

If there is potential recourse available, then make sure to write down the next steps and keep this with the statement. Any telephone calls, letters written or action taken should be recorded also so that there is proof, if it is needed, that some action was taken. Make copies of all letters sent and received and keep these together with the statement. It is advisable to keep the person informed of the actions that have been taken and the outcomes of such actions.1

Affidavits

An affidavit is a written statement (see above) that a person can swear to as being the truth. An affidavit must contain true and honest facts, and the person who made it must swear to a Commissioner of Oaths that it is the truth. A Commissioner of Oaths can be a magistrate, postmaster, bank manager, lawyer, in some cases a priest or a social worker, or a member of the South African Police Services (SAPS).

Other ways of collecting information

If the incident took place at a certain location, it is a good idea to go to that place, and take notes and/or take pictures. It may be helpful if pictures are taken, especially if, for example, the person says that he/she was abused and has bruises or scratches that corroborate the story (make his/her story seem true), as these may be used later when trying to resolve the case.

Sometimes, the problem or incident can involve other people, or could have happened in front of others. It is a good idea to get a statement from these people also, as it can corroborate the story. Take a statement from each of these people separately, if possible, and compare the stories. Ask for clarification if there are discrepancies in the information that comes from the different people. Keep the statements along with the statement of the primary person affected by the violations.

Tool 4.2

Human rights violations – laying a charge

The statement will be the basis for what is said under oath at the trial, so it is important to be clear and confident of what it contains. One should not sign the statement until one is happy with it, and ask for a copy before leaving the police station.

If a person has been a victim of a crime, and the police have either not been informed or have not laid a criminal charge, the following steps are to be followed to lay a criminal charge:

- **Make a statement.** The person must first make a statement to a paralegal or someone else who can take the statement and assist with the case. If possible, the paralegal should take pictures, visit the scene of the incident and also interview other witnesses.

- **Go to a doctor.** If the case involves assault, rape or other injuries, it is important to go to the doctor as soon as possible for a medical check-up.

- **Report to the charge office.** As soon as possible after making the statement, go to the charge office at the nearest police station (the police station that is nearest to where the incident occurred), preferably with the person who took the statement.

- **Make a statement to the police.** The complainant will be asked to make a statement to the police. The police must take the statement, and they cannot refuse to listen or refuse to take the statement. The statement should be the same as that given to the paralegal or person who helped in the first case. The statement will be the basis for what is said under oath at the trial, so it is important to be clear and confident of what it contains. One should not sign the statement until one is happy with it, and ask for a copy before leaving the police station. A person has a right to his/her statement.

- **Ask for a police reference number.** The police reference number is the number in the register where the police are supposed to keep a record of all complaints made at the charge office. This is proof that a complaint was made to the police.

- **Ask for the case-docket number.** After the statement is made and the complaint registered, the police are supposed to open a case docket and investigate the criminal charge against the person who committed the crime. It is important to ask for the case-docket number, as this will assist in checking on the progress of the case.

- **Check on the progress of the case.** Based on the case-docket number, it is possible to find out who the investigating officer working on the case is. The investigating officer is the police officer who is in charge of investigating the case.

Take note of his/her name and then communicate with him/her regularly on the status of the case. While it may be difficult to contact the investigating officer, a complainant has a right to be kept informed of any new developments and how the investigation is proceeding.

- **The criminal case.** After the investigation is completed, the case docket is handed over to the local office of the Director of Public Prosecutions. The prosecutor will decide whether or not there is enough evidence to prosecute the person against whom charges were brought by the complainant. If the case goes ahead, the complainant will receive a formal legal notice (a ‘subpoena’) to be in court to give evidence on a particular date and time. On this date, the complainant should go to court early so that the prosecutor can explain what is happening and what kinds of questions he/she will be asked. The complainant has a right to read over his/her statement again before giving evidence.²

There are several important elements of the advocacy plan, including:

1. **The statement of objectives**

   It is particularly useful if the objectives are stated in a SMART format, i.e., the objectives are specific, measurable, attainable, reasonable, and time-bound. Some examples of SMART objectives are: Raise the level of knowledge on and understanding of HIV/AIDS of the police force in the municipality by 25% by the end of the year; and incorporate the teaching of HIV/AIDS and human rights into the high school curriculum of at least 20% of public schools in the district by the end of the year.

2. **Identification of the principal targets of the advocacy campaign**

   An advocacy campaign may have many ‘targets’. Targets are those who have the capacity to respond and bring about the desired changes the organisation/coalition is seeking. However, the targets may have varying degrees of influence, and because resources are limited, it is important to focus on those that are essential to achieve the desired outcomes. They would include those with the greatest influence and power to bring about the desired changes. For example, if the objective is to have HIV/AIDS and human rights incorporated into the high school curriculum, then the key targets would include officials in the Department of Education and the Human Rights Commission.

3. **Identification of potential allies/supporters who may be interested in the issue and may be mobilised in the advocacy campaign activities**

   This again broadens the support base for the issue, and increases the pressure that is placed on the relevant targets. It is very useful to try to engage the media and community leaders to present the problem and the proposed solution.

4. **List of activities**

   The plan of action should also contain a list of activities that will be undertaken during the advocacy campaign. These activities can include, for example, having forums, discussion meetings and information dissemination meetings at community level; production and distribution of information, education and communication (IEC) materials to key targets; holding press conferences; writing press releases and letters to the editor; presenting on radio and television; circulating a petition; holding a mass demonstration; organising cultural shows/activities like concerts and plays; or lobbying Parliament on the issue. The list of activities should include agreed upon dates for completion, the resources required for each activity, including human, material and financial requirements, and should include ideas on where to fundraise for the resources, if required, and the people/group responsible for each activity.

5. **Implementation, monitoring and evaluation of the plan of action**

   Once the plan of action is implemented, monitoring becomes necessary. This involves keeping track of how the various activities are being carried out, the problems encountered, adjustments that need to be made to the plan, and what results are being achieved. The information gathered during the monitoring and evaluation will be useful for developing any future initiatives. Remember that change may be slow and that in many cases advocacy requires ongoing engagement. It can take several months to several years to achieve the objectives.
An indicator is a tool that helps you and your organisation know how far your organisation is from achieving your goals (such as reducing stigma) and whether you are headed in the right direction. Choosing the right indicator is essential for effectively evaluating your progress. The right indicator should be relevant to your context, be easily understandable to everyone, be easily measured and provide reliable information.

The HIV/AIDS stigma indicators for the Siyam’kela project were developed in a year-long process of expert consultations and focus group discussions across South Africa. They are divided into two types: external stigma (actual experiences of discrimination such as harassment or violence) and internal stigma (felt or imagined stigma evidenced in ways such as an unwillingness to seek help). As you read these indicators please also think about how they might be affected by factors such as gender, race, age, sexual orientation and geographic location.

The proposed indicator themes to measure internal stigma are:

8. Self-exclusion from services and opportunities, measured by, for example, the number of PLHA who choose not to access existing support services such as grants.

9. Perception of self, measured by, for example, the number of PLHA who show low self-esteem on reliable psychological tests as a result of their HIV status.

10. Social withdrawal, measured by, for example, the number of PLHA who report they have withdrawn from intimate relationships since their diagnosis.

11. Overcompensation, measured by, for example, the number of PLHA who report they are working harder than other colleagues to make up for being HIV positive.

12. Fear of disclosure, measured by, for example, the number of PLHA who have disclosed their HIV status. Note that this in an inverse measure of stigma: high levels of disclosure could mean that stigma is low in your organisation.

Most of the examples of measurement of the indicators given above apply to organisations where there are fairly high levels of disclosure. If disclosure levels are low you can also measure the indicator by asking staff to imagine the kinds of stigma they think they would experience if they were HIV positive. All the indicators listed above are explained more fully in the Siyam’kela document on HIV/AIDS stigma indicators.
## 5. Workshop activities

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<th>Theme</th>
<th>Description</th>
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</table>
**Activity 1**

**Introducing each other**

**Objectives**

By the end of this activity participants will:

- be more familiar with other participants
- understand the workshop’s aims, and how these relate to their expectations
- understand how the workshop will be evaluated
- have a group representative for each day of the workshop
- understand the logistics of the workshop.

**Suggested process**

- Ask participants to pair up with someone they do not know well.
- Ask the pairs to carry out a mini-interview with each other, by asking about each other’s:
  - name, position and organisation
  - work they do in relation to HIV and AIDS
  - expectations and fears about the workshop
  - one personal quality which they bring to the group.
- Bring everybody back together, and each person to introduce themselves.
- Facilitators should present the participants with the objectives and schedule for the workshop, ensure that this addresses expectations, and where not, how this can be dealt with (either by adjusting the programme, or finding another opportunity for the participant to address their need).
- Explain how the workshop will be evaluated, including the idea of having a group representative to be the eyes and ears of the participants.
- Ask for volunteers to be the group representative for each day of the workshop.
- Make a brief presentation about the logistics for the workshop. Include information about:
  - the venue
  - lunch breaks and tea breaks
  - allowances for participants, such as travel expenses.
- Give participants the opportunity to ask questions about the logistics and to share any concerns they have.
Setting ground rules

Objectives
By the end of this activity you should be able to create a learner-friendly environment by deciding how the group will behave during the workshop.

Suggested process
• Explain the aim of this activity.
• Facilitate the development of a set of ground rules about how the participants will behave and relate to each other during the workshop. Ask them to agree on individual roles and group responsibilities in relation to:
  • active listening
  • time-keeping
  • documentation
  • logistics, such as arranging the chairs and keeping the room tidy
  • taking action if some participants do not follow the ground rules.
• Ask one of the participants to write the ground rules on a flipchart and display it on the wall.
• See Notes to Facilitator to assist in the brainstorm.

Examples of ground rules
• Personal information that is shared in the group is confidential and remains in the group. If you wish to discuss your own personal experience in the group with, say, your partner, that’s fine, as long as you respect the confidences of others.
• Never pressurise anyone else to do or say anything if they are reluctant to.
• Do not feel pressurised to partake if you do not wish to.
• Take responsibility for yourself. You need to take responsibility for what you are and for what happens to you.
• Let one person speak at a time and don’t start subgroups. If you cannot hear, or if you feel bored, say so.
• Focus on feelings. Experiencing something emotionally and understanding it intellectually are two very different things.
• Engage in feedback – tell others how you feel about them.
• Be adventurous and take risks. You may feel embarrassed and foolish but “nothing ventured, nothing gained”.
• Reflect on your experiences during the group after the session is over. This is often as enlightening as the experience itself.
• Participate – everyone has something valuable to contribute.
• Don’t dominate – give space to others to ask and answer questions, and to report back from small groups.
• Time keeping is important, especially at breaks and lunch time.
• Attend the whole workshop – it is disturbing to have participants leaving and re-joining.
• Cell phones should be OFF! Have a penalty for ringing phones or people sending text messages.
Activity 3

Presenting participants’ organisations

Objectives

By the end of this activity participants will have:

- familiarised themselves with different organisations, their work with HIV/AIDS and stigma, and strengthened networks.

Suggested process

- Give participants 10 minutes to display the materials about their organisations and to prepare their presentations. Ask them to base their presentations on the following questions:
  - Where is your organisation based and with whom does it work?
  - What are your organisation’s key activities?
  - What are the key opportunities and challenges that your organisation faces in relation to the subject of the training workshop (stigma)?
- Facilitate the presentations by asking the representatives of each organisation to stand by their display and make a 5-minute presentation. Emphasise the need to keep within this time-frame.
- When all the presentations have been made, summarise them by highlighting that:
  - The participants bring a valuable range of knowledge, skills and experiences with them.
  - The information that has been presented will provide useful reference points during the workshop, especially in terms of adapting concepts to organisations’ practical work with communities and networking.

Suggested time

60 minutes (will vary according to organisations represented)

Materials

None

Resource pack – To reduce stigma related to HIV and AIDS
Theme 2:
Setting the scene - exploring our thoughts and attitudes about HIV and AIDS

Activity 4

Attitudes and values

Objectives
By the end of this activity participants will:

- be sensitive to the range of attitudes and values related to HIV and AIDS
- understand and respect diverse opinions
- have insight into their own attitudes and values and how this may influence their HIV and AIDS work.

Suggested process

- Explain that this exercise will help us understand viewpoints that are different from our own, and to consider how these attitudes and beliefs about HIV and AIDS might affect the way we treat people who are HIV positive. State that there are no ‘right’ or ‘wrong’ answers and that we are all entitled to our own opinions.

- Ask participants to gather in the centre of the open area. Direct their attention to the signs.

- Explain that you will be reading a series of value statements. After you read a statement aloud, the participants will decide whether they agree or disagree with the statement, or if they are unsure of their response. Those who agree will move and stand by the ‘Agree’ sign. Those who disagree will move and stand by the ‘Disagree’ sign and if you are not sure, to the ‘Don’t know’ sign. If they hear something that causes them to change their opinion during the course of the activity, they may move from one area of the room to another.

- The facilitator remains neutral by not offering interpretations for the statement that would influence participants’ responses. However, he or she can share factual information to clarify matters, as needed. Read a statement and then get feedback as to why participants chose that point of view.

- Ask the participants to return to their seats for a group discussion. Facilitate a discussion to explore differences of opinions and values more deeply, based on the following questions. Use the questions outlined in Notes for facilitators to guide discussion.
Additional notes for the process

- Select some of the statements you feel are relevant to the group. Create new statements as well.
- Arrange the training room so that there is adequate open space for participants to assemble near the ‘Agree’ and ‘Disagree’ signs.
- During this exercise, it is important to emphasise that there are no right or wrong answers. We all respond to the statements based on our own beliefs and values, and the purpose of this activity is to help explore these differences where they exist.
- In order to explore a range of issues, you may need to limit discussion of each statement to comments from one or two participants representing each position.
- If everyone moves to one side of the room (e.g., everyone ‘agrees’ with the statement), you can ask the group how a person with the opposite opinion might defend their position. Alternatively, facilitators can step into that spot and speak out on the opinion, clarifying to the group that they are just stating the rationale for that position in a direct and straightforward manner.

Sample value statements

- People with HIV should stop having sex.
- Putting sex workers in prison will stop HIV.
- All hospital patients should be tested for HIV.
- Virginity testing is effective in preventing HIV/AIDS.
- PLHA should be discouraged from getting pregnant.
- PLHA should be encouraged to be sterilised.
- HIV/AIDS is punishment for humankind’s sins.
- Condoms should be made available at schools.
- Sex education encourages young people to be sexually active.
- If the law was more strict and properly applied with regards to sex workers, there would be a reduction in the spread of HIV/AIDS.
- It should be made easier to dismiss PLHA who are not working properly; they are a drain on the business and economy.

Guidelines for group discussion

- How did you feel during this exercise? What was it like for you?
- Were there any opinions or values expressed that surprised you?
- Which statements were the most controversial and why?
- How can you explain the differences between individuals in this group?
- How did you feel when other people expressed values and beliefs that were different from yours?
- Why is exploring these issues important?
- How might attitudes and beliefs affect the way you behave toward or treat colleagues or clients?
- How do our fears about HIV and biases towards HIV-positive people or those thought to be infected or at risk influence our values, opinions and actions?
- How can we keep our own values from influencing our work in a negative way?
- How might you address some of these difficult issues in your workplace?
Theme 3: Introducing stigma

Introduction

This section gets participants to understand stigma and that:

- stigma exists and takes many forms – rejecting, isolating, blaming and shaming, etc.
- we are all involved in stigmatising, even if we don't realise it
- stigma hurts people living with HIV and AIDS and those suspected of having HIV
- stigma is harmful to ourselves, our families, and communities
- we can make a difference by changing our own thinking and actions.

This section also gets participants to own the problem — to recognise that we are all involved in stigmatising people living with HIV and AIDS. It is not someone else’s problem. We are all part of the problem, even if at first we don't recognise it.

The section starts with people's own experience of and feelings about being stigmatised and stigmatising others. The aim is to get people to connect to the issue on a personal, emotional level, rather than on a theoretical level (through a definition). People can see how stigma affects people through their own experience of being isolated or excluded – and how it hurts.

Then the rest of this section looks at what stigma means for people:

- What are the forms of stigma? What does it look like – in our attitudes, language, and behaviour?
- What are the effects of stigma – on PLHA, families, communities, people's access to health services, etc.?
- What are the root causes of stigma?

The forms, effects and root causes are explored through a series of optional activities.

Stigma – some introductory notes

We all stigmatise. We stigmatise when:

- we say things like “she was promiscuous” and “he deserves it”
- we do things such as isolating PLHA, excluding them from decision-making, etc.

The main causes of stigma include:

- insufficient knowledge, false beliefs and fears about a) how HIV is transmitted; and b) the life potential/capacity of PLHA (no immediate death)
- moral judgements about people who have been sexually promiscuous
- fears about death and disease
- lack of recognition of stigma.

The main forms of stigma include:

- physical and social isolation from family, friends, and community
- gossip, name calling, and condemnation
- loss of rights and decision-making power.

Other forms of stigma include:

- self-stigma – PLHA blaming and isolating themselves
- stigma by association – the whole family affected by stigma
- stigma by looks/appearance/type of occupation.

The effects of stigma include:

- being kicked out of family, house, work, rented accommodation, organisation, etc.
- dropping out of school (resulting from peer pressure – insults)
- depression, suicide, alcoholism
- not accessing services
- social withdrawal
- not taking advantage of opportunities.
Objectives
By the end of this activity participants will be able to:

- identify different forms of stigma in different contexts
- describe how stigma affects people with HIV.

Suggested process

Step 1: Picture discussion
- Divide into groups of 2-3 people.
- Ask each group to select one of the pictures.
- Ask them to discuss: "What do you see in the picture? How does this picture show stigma?"

Step 2: Report back
- Put up one picture at a time and ask the group to present their analysis.
- Record points on flipchart sheets.
- One other recorder should make a running list of common issues, which should be presented at the end.

Man seated all alone on a bed (A)
No one is caring for him. Utensils under bed – shows that people are not sharing utensils with him. Looks lonely and worried – seems to have lost all hope.

Parents pushing pregnant daughter out of house (B)
Unwanted pregnancy. Is she HIV positive? Maybe she will get abortion, drop out of school, or become a sex worker to survive.

Woman sitting all alone crying (C)
Maybe she has just learned that she is HIV positive and people are rejecting her. Depressed, hopeless, anxious. No one to share her problems with.

Sick man in bed with children visiting (D)
Looks depressed. Worried about future for his children once he dies. His children look worried – they don’t know what to do if their father dies.

Activity 5

Suggested time
1 hour

Materials
Selection from stigma pictures

Write the quotes in this section and any others on cards and decorate the walls with them. This helps to create an interesting learning environment.
3. Intervention options

C

5. Workshop activities
Step 3: Summarise as follows:

Effects:
- PLHA feeling isolated, rejected, condemned, forgotten, useless
- kicked out of family, house, work, rented accommodation, organisation, etc.
- drop out of school (resulting from peer pressure – insults)
- depression, suicide, alcoholism
- not accessing services
- not taking advantage of opportunities
- social withdrawal.

Forms of stigma:
- internal and external stigma
- isolation, insults, judging, blaming
- self-stigma – PLHA blaming and isolating themselves
- stigma by association – whole family affected by stigma
- stigma by looks/appearance/type of occupation.

Activity 6

Objective

By the end of this activity participants will be able to:

- Participants describe some of their own personal experiences concerning stigma.
- They identify some of the feelings involved in being stigmatised or stigmatising others.

Suggested process

Step 1: Our experience of being stigmatised – individual reflection

- Ask participants to sit on their own at a distance from other participants.
- Then say: “Think about a time in your life when you felt isolated or rejected for being seen to be different from others – or when you saw other people treated this way”.
- Explain that this does not need to be examples of HIV stigma – it could be any form of "isolation or rejection for being seen to be different".
- Ask them to think about:
  - what happened?
  - how did it feel?
  - what impact did it have on you?

Step 2: Sharing in pairs (optional)

- Ask participants to share experiences in pairs. Tell them: “Share with someone with whom you feel comfortable.”

Step 3: Report back

- Invite participants to share their stories in the large group.
- There is no compulsion: people will share if they feel comfortable.
Step 4: Stop-start drama
- Invite some of the storytellers to act out their stories in short role-plays (with other participants playing the other roles).
- This activity helps to make the stories come alive and to see the feelings involved – the pain in being rejected, isolated, or condemned.
- At the end of each scene ask the role players:
  - “How did you feel to be stigmatised?”

Step 5: Our own experience of stigmatising others – individual experience
- Ask participants to sit on their own.
- Then say: “Think about a time in your life when you isolated or rejected other people because they were different”.
- Ask them to think about:
  - what happened?
  - how did you feel?
  - what was your attitude?
  - how did you behave?
- Then ask participants to write down any thoughts, feelings, or words that they associate with stigma.

Step 6: Report back
- Ask each participant to read their list out loud and record the points.
- Then discuss:
  - what feelings are associated with stigma?

Step 7: Summary
Pull together the main points, emphasising that we have all felt ostracised or treated like a minority at different times in their lives. And it is okay to feel like that because you are not alone – we have all experienced this sense of social exclusion.

Resource pack – To reduce stigma related to HIV and AIDS

Experience of being stigmatised from previous workshops
- Being fired from a job without any clear reasons for being dismissed and then laughed at or shunned by fellow workers.
- Going to another region of the country and not being able to speak the local language – as a result feeling isolated and lonely and thinking that people were making fun of me.
- Being left-handed: as a child my left hand was tied up in a cloth to stop me using this hand. This made me feel different from other people – like an outcast – children laughed at me.

Experiences of stigmatising others
- Using abusive language to street children or orphans.
- Avoiding shaking hands with people who are suspected to have HIV.
- Refusing to speak up for an HIV-positive friend at the hospital.

How did you feel when you were stigmatised?
- Depressed
- Feeling judged
- Outcast
- Alone/loneliness
- Unaccepted
- A failure
- Degraded
- Teased
- Dehumanised: “people no longer take me seriously”.

Being left-handed: as a child my left hand was tied up in a cloth to stop me using this hand.
Objective

By the end of this activity participants will be able to:

- define stigma and give examples.

Suggested process

Step 1: Cardstorm – What is the meaning of stigma?

- Hand out cards.
- Ask participants to write on cards their own definition, in their own words: "What do you think is the meaning of 'stigma'?"
- Encourage people to give examples of stigma or define it.
- Then explain the definition below or give it out as a handout.

Experiences from previous workshops (Zambia)

- Deep feeling one can have, which makes one feels disrespected or unloved.
- I feel stigmatised in my work as an AIDS educator – people tease me about distributing condoms and call me "Mama Condom".
- PLHA being blamed for their infection and told they deserve it.
- People running away from you because of a disease you have.
- Feeling ashamed because one has HIV/AIDS or TB.
- Fear of disclosing one's disease to others.
- Self-stigma – PLHA react to and begin to accept negative judgements of society.

Stigma: is a mark of disgrace associated with a particular circumstance, quality or person. Stigma is a spoilt identity.

Discrimination: make an unjust distinction in the treatment of different categories of people, especially on the grounds of race, sex, or age.

[The Concise Oxford Dictionary, 2001]
Other important dimensions

- Often people do not understand the word ‘stigma’ in English.
- Difficult to find a word in other languages, which is equivalent. Use a phrase.
- Differs in intensity – sometimes blatant, sometimes subtle.
- Targeted mostly at people who are assumed to be HIV positive.
- Targeted at stereotyped and scapegoated groups (women, sex workers).
- Other diseases (TB) are stigmatised because of HIV.
- AIDS disfigures, so stigma changes according to the stage of the disease.
- Stigma increases as the symptoms of the disease become more visible.
- HIV, sex, and death – value laden.
- Motives for stigma change according to the setting.
- Disrupts social relations.
- People fear that HIV is very contagious.
- People hide their stigmatising attitudes.
- Discrimination and human rights.

Stigma is different to discrimination. To stigmatise is to label someone, to see them as inferior because of an attribute they have. Discrimination is an action which comes as a result of stigmatisation, prejudice, stereotyping, etc.

Two types of stigma

Internal stigma – self-hatred, shame, blame – people feel they are being judged by others, so they isolate themselves. PLHA practice “self-stigma” – isolate themselves from their families and communities.

External stigma or enacted stigma or discrimination - perceptions, feelings or actions towards PLHA.

Stigma is a process

- Point out or label differences – he is different from us – he coughs a lot.
- Attribute differences to negative behaviour – his sickness is caused by his sinful and promiscuous behaviour.
- Separate ‘us’ and ‘them’ – for example, shunning, isolation, rejection.
- Loss of status and discrimination – loss of respect, isolation.
Activity 8

Naming stigma in different contexts

Objectives
By the end of this activity participants will be able to:

- identify different forms of stigma in different contexts
- identify how stigma affects people with HIV
- begin to identify some of the root causes of stigma.

Suggested process

Step 1: Select a context
Ask participants to select a context and to:

- identify forms of stigma which occur in that context
- say what are the attitudes here
- suggest why people develop such attitudes.

Try and get all the contexts represented. If not, you can discuss the context with the whole group.

Step 2: Report back and discussion
Get each group to give feedback, noting the main points on a flip chart as they report back.

Discuss some of the following questions:

- what are some of the common features across the different contexts?
- what are the attitudes/feelings in all contexts towards PLHA?
- what are the effects on people who have been stigmatised?
- what are the root causes of stigma and discrimination?
Activity 9

Effects of stigma on different players

Objectives
By the end of this activity, participants will be able to:

- identify the effects of stigma on different individuals, groups and institutions
- explain how stigma creates a barrier to health services and programmes for PLHA.

Suggested process

Step 1: Rotational brainstorming - How stigma affects different groups

- Divide into groups.
- Assign one group to each topic.
- Ask groups to brainstorm how does stigma affect their target group. Ask participants to look for both immediate effects – shame, isolation, depression, hiding one’s status; and spin-off or larger effects – loss of jobs, dropping out of school, suicide, etc.
- After 3 minutes shout “Change!”
- Ask groups to move to the next topic and add points.
- Continue until groups have contributed to all topics.

Step 2: Report back
Ask the original group to present each topic – the main points – and then ask for clarifications and additions. Note common or unusual points.

Step 3: Group discussion
Ask the group “How does HIV stigma affect the take-up of HIV and AIDS services or programmes?”

Try out this activity in your own group – faith group, women’s group, youth group or workplace. Get the group to discuss the effect of stigma on group members or their families.

Try out this activity in your own group – faith group, women’s group, youth group or workplace. Get the group to discuss the effect of stigma on group members or their families.

This is a variation on Activity 5 – see which will be most appropriate for your group.

Resource pack – To reduce stigma related to HIV and AIDS

Put up blank sheets of flipchart paper on different walls of the room, with a target group written at the top of each sheet:

- PLHA
- family
- community
- women
- men
- children
- stigmatisers
- health services
- workplace
- education
- social relations
- sex workers
- youth

Try out this activity in your own group – faith group, women’s group, youth group or workplace. Get the group to discuss the effect of stigma on group members or their families.

Family: Shame, disgrace, loss of face – family’s reputation, status, and honour destroyed. Rejection by community. Deny that there is a problem. Family conflicts – blame each other for loss of family reputation. Stigma reinforces existing power relations – wife blamed for not raising child properly. Marriage collapses. Children dumped with relatives. Loss of income when breadwinner dies. Property grabbing. Family can benefit from special resources for PLHA; or lose out on services due to fear of stigma.


Health services: PLHA stop using services – testing, counselling, treatment, ART, MTCT. Lack of resources and heavy workloads. Burnout and fears – health workers desert AIDS work. Climate of silence around health care.

Stigmatisers: Sense of power. Double standard – stigmatisation may cover up their own fears about HIV infection. Culturally acceptable – others are doing it – deep rooted.
Objectives

By the end of this activity participants will be able to:
- identify different forms of stigma and how stigma affects people
- identify some of the root causes of stigma.

Suggested process

**Step 1: A problem tree**
Participants should be asked to draw a problem tree, showing forms of stigma (main trunk), effects (branches) and causes (roots).

**Step 2: Dig deeper – ask: "But why?"**
- Look at the causes and dig deeper, asking "But why?" to look for deeper causes.

Optional:
Set up a topic group for each cause. Ask groups to do a detailed analysis.
Causes could include:

- Poverty; poor knowledge; fear of disease; poor health care; fatalism; media; gender; misconceptions; inferiority and superiority complex; government policy.
- Morality: view that PLHA are sinners, promiscuous, unfaithful, ‘sleeping around’.
- People’s beliefs about pollution, contagion, impurity.
- Fear: fear of infection, fear of the unknown, fear of death.
- Ignorance: lack of knowledge makes people fear physical contact with PLHA.
- Gender and poverty: women and poor people more stigmatised than men/rich people.
- Prejudice: tendency to judge others.

Example of additional analysis of poverty

- Poverty can lead people to stigmatise.
- Poor women are forced by poverty to do transactional or commercial sex.
- Poor people, who are malnourished, are stigmatised by looks. Cannot hide their HIV condition in the way that a rich person can – easily seen by neighbours. Already stigmatised as poor people.

Example of additional analysis of ignorance

- Lack of knowledge on how HIV is transmitted.
- Believe that casual contact with PLHA can result in infection.
- Denial: some have the knowledge but don’t believe it – think that they can still get HIV through casual contact.

Effects could include:

- Loss of promotion, education, accommodation. Decline in school performance or dropout from school. AIDS orphans and street kids. Abuse or poor treatment by relatives.
- Deprived of medical care, health staff argue this is a “waste of resources”. Sent back to the village and property grabbing. Quarrels within the family - argue over who is responsible for this situation and who will take care of the sick PLHA. Stop making use of clinics, VCT programme, and HBC programme. Reluctance to take medication. No treatment. Spread of infection.

Forms of stigma could include:


The but-why method is a general example to show how to dig deeper:

The child has a septic foot.
"But why?"
"Because she stepped on a thorn."
"But why?"
"Because she has no shoes."
"But why has she no shoes?"
"Because her father cannot afford to buy her any."
"But why can he not afford to buy her shoes?"
"Because he is paid very little as a farm labourer."
"But why is he paid so little?" etc. etc.

Theme 4: Exercises which address fears and misinformation

Activity 11

Assessing knowledge levels

Objectives
By the end of this activity participants will be able to:

- understand basic facts and information about HIV and AIDS as a basis for dealing with myths
- explain how myths and misinformation contribute to the development of stigma.

Option 1: True or false?

Suggested process
Go through each question, involving the group in discussion. Use the Notes for facilitators on page 106 as a guide for discussion.

Suggested statements to put on cards or flipchart

True or false?

- Having sex for money will give you HIV.
- A recently infected person will show no symptoms of AIDS.
- Kissing HIV-positive people can be dangerous.
- If you wash yourself after sex you will not get infected with HIV.
- All people with TB have AIDS.
- There is no cure for AIDS.
- You can become infected with HIV from oral sex.
- You will not get HIV by having sex with a virgin.
- Donating blood can give you HIV.
- You can get HIV from mosquitoes.
- Condoms will stop you becoming infected with HIV.
- If you stick to one partner you won’t become infected with HIV.
- You can’t get AIDS from a person who looks healthy.
- Anal sex carries a risk of HIV.
- People with HIV should stop having sex.
- People with many sexual partners are most at risk of HIV infection.
- Putting sex workers in prison will stop HIV.
- All hospital patients should be tested for HIV.
- If a couple are both HIV positive, they should not worry about safe sex.
**Option 2: Sharing knowledge**

**Suggested process**
- Put up flipchart paper on different walls of room and put a question at the top of each sheet
  - What is HIV?
  - What is AIDS?
  - How can you get HIV?
  - What are the signs/symptom of HIV?
  - What are the signs/symptoms of AIDS?
  - How can you prevent HIV/AIDS?
  - How can you live best with HIV?
- Concerns and fears
- Ask participants to walk around in pairs and write down:
  - what they know about the topic
  - any questions
  - concerns or fears.
- Then review each sheet and respond to questions, concerns, or misinformation.

**Options**

**Option 3: All the things we want to know about AIDS**

**Suggested process**
- Divide participants into pairs.
- Hand out 5 blank cards to each pair.
- Ask pairs to write on each card questions or something they want to know about HIV and AIDS and tape the cards on the wall.
- Eliminate repetition.
- Then discuss each of the questions, with participants contributing their ideas. Help to sort out facts from misinformation. If any question is unclear to both trainers and participants, ask the group to research this question for homework.

**Option 4: Risk continuum**

**Suggested process**
- Write on cards different ways in which HIV may be transmitted (see examples below).
- Tape up the continuum across the front wall – high risk, low risk, no risk, don’t know.
- Hand out 2-3 cards to each participant (the cards are listed in the box below).
- Ask participants to tape their cards under the chosen category.
- Then discuss their choices.
- Put each of these behaviours in the table below on a card.

**Examples of how HIV can be transmitted**

<table>
<thead>
<tr>
<th>Risk level</th>
<th>Ways in which HIV may be transmitted</th>
</tr>
</thead>
<tbody>
<tr>
<td>High risk</td>
<td>Many sexual partners</td>
</tr>
<tr>
<td></td>
<td>Sex without condom</td>
</tr>
<tr>
<td></td>
<td>Anal sex</td>
</tr>
<tr>
<td></td>
<td>Dry sex (herbs to make the vagina dry)</td>
</tr>
<tr>
<td>Medium risk</td>
<td>Breastfeeding</td>
</tr>
<tr>
<td></td>
<td>Mother-to-child transmission</td>
</tr>
<tr>
<td>Low risk</td>
<td>Blood transfusion</td>
</tr>
<tr>
<td></td>
<td>Non-penetrative sex</td>
</tr>
<tr>
<td></td>
<td>Kissing</td>
</tr>
<tr>
<td></td>
<td>Cleaning up spilled blood</td>
</tr>
<tr>
<td>No risk</td>
<td>Cleaning a PLHA</td>
</tr>
<tr>
<td></td>
<td>Shaking hands</td>
</tr>
<tr>
<td></td>
<td>Sharing cups</td>
</tr>
<tr>
<td></td>
<td>Sharing sheets, towels, clothing</td>
</tr>
<tr>
<td></td>
<td>Using toilets</td>
</tr>
<tr>
<td></td>
<td>Bites from a mosquito, bed bug or flea</td>
</tr>
<tr>
<td></td>
<td>Sharing food</td>
</tr>
<tr>
<td></td>
<td>Sleeping in room of a PLHA</td>
</tr>
</tbody>
</table>

Don’t know
Activity: True or False

- **Having sex for money will give you HIV.** True – if your partner is HIV positive and infects you with the virus...but False – if your partner is HIV negative you won’t get HIV even if he paid for sex. If you use condoms correctly and consistently you can stay safe. It is important to think of the reasons as to why you are having sex, and the risks involved. Very often young people who have sex for money (or other gifts or favours) are not in a position to negotiate issues around safe sex.

- **A recently infected person will show no symptoms of AIDS.** True – symptoms only appear in the later stages of the disease, sometimes only after 5-7 years.

- **Kissing HIV-positive people can be dangerous.** False – kissing is a low-risk activity. Your risk is increased if you have open sores in your mouth. The risk of getting HIV from spit is extremely low.

- **If you wash yourself after sex you will not get infected with HIV.** False – you cannot wash the virus off.

- **All people with TB have AIDS.** False – although there is a close link between HIV and TB. People with HIV are more at risk of getting TB. TB is highly infectious and the resistance of an HIV person is extremely low, particularly to TB. But not all HIV-positive people have TB, and not all people with TB are HIV positive.

- **There is no cure for AIDS.** True – there is only treatment but there is no cure.

- **You can become infected with HIV from oral sex.** True – but the risk is not as high as penetrative sex, the risk is increased if you have sores or bleeding gums.

- **You will not get HIV by having sex with a virgin.** False – the person may have contracted HIV from other means – from the mother, or through a blood transfusion, or through intravenous drug use or dirty needles. Furthermore, this belief is putting virgins at risk as the man may be HIV positive. It also may be a violation of her rights and the law if it is forced and/or she is a minor.

- **Donating blood can give you HIV.** False – South Africa has high standards in terms of blood donation. New needles are used for each donor.

- **You can get HIV from mosquitoes.** False – if it did there would be equal numbers of people of all ages with HIV.

- **Condoms will stop you becoming infected with HIV.** True – if used correctly and consistently.

- **If you stick to one partner you won’t become infected with HIV.** False – it is only true if both partners have only one sex partner – each other – and both were HIV negative when the sexual relationship started.

- **You can’t get AIDS from a person who looks healthy.** False – can’t tell HIV status from appearance.

- **Anal sex carries a risk of HIV.** True – anal sex often results in abrasions and bruising which provides an entry point for the virus. The rectum and anus is an area in the body rich in CD4 receptors needed for the virus to penetrate into the body.

- **People with HIV should stop having sex.** False – they need to be very careful, honest with their partner, and should practise safe sex, to protect themselves and others from infection. Should the condom break they are putting their partner at risk.

- **People with many sexual partners are most at risk of HIV infection.** True and false – unsafe sex, whether with one partner or many, puts you at risk of HIV infection. The more sexual partners you have, the more of a risk you and your partner are taking. This is why young people are encouraged to reduce the number of sexual partners, and to protect themselves and others when having sex. If you have many partners but practise safer sex consistently, your risk is low.

- **Putting sex workers in prison will stop HIV.** False – arresting and prosecuting of sex workers does not prevent HIV. Rather, the use of condoms with clients and treatment of STIs can help prevent the spread of HIV.

- **All hospital patients should be tested for HIV.** False – a patient may only be tested for HIV when he or she has been fully counselled about the implications of undergoing the test. An HIV-positive patient is at risk of becoming ill from other patient’s infections and needs protection from them rather than the other way around. The basic infection control guidelines in place in a hospital protect both health workers and patients.

- **If a couple are both HIV positive, they should not worry about safe sex.** False – there are different strains of HIV, so an HIV-positive couple should still protect against infection with new strains of HIV by using condoms. A couple can also push up each other’s viral loads faster when not using a condom.
### Suggested process
Divide participants into small groups or work with the whole group. Write the questions on a flipchart, and then answer them.

- Can mosquitoes transmit HIV from human to human?
- Can HIV be transmitted through razor blades or sharp instruments?
- Can I get HIV by touching someone who has open cuts and sores?
- What about cleaning up the diarrhoea of an HIV-positive patient?
- How long can you live if you get HIV/AIDS?
- Is it true that condoms are not really safe?
- Is there any cure for AIDS?

### Suggested answers

<table>
<thead>
<tr>
<th>Question</th>
<th>Answer</th>
</tr>
</thead>
<tbody>
<tr>
<td>Can mosquitoes transmit HIV from human to human?</td>
<td>No. The HIV virus cannot live outside the human body. Mosquitoes do not inject blood into humans, they suck blood.</td>
</tr>
<tr>
<td>Can HIV be transmitted through razor blades or sharp instruments?</td>
<td>There is a slight risk — where a razor is being used quickly to make incisions or cuts on many people one after the other without washing it. It is better and more hygienic anyway to sterilise sharp instruments by boiling them, or use new razors every time. In terms of sharing razors to shave or cut hair — if a razor is covered in blood you would probably not use it anyway — or you would wash it thoroughly.</td>
</tr>
<tr>
<td>Can I get HIV by touching someone who has open cuts and sores?</td>
<td>No. Unless someone is covered in blood and you are injured badly yourself with open wounds, then there is no risk. Your skin protects you. If you are bleeding, your blood flows outwards, it does not suck things into your bloodstream! Good hygiene would mean that if you are caring for someone (with HIV or not) and they are bleeding, you would use gloves or cover your hands, and wash well before and afterwards.</td>
</tr>
<tr>
<td>What about cleaning up diarrhoea of an HIV patient?</td>
<td>There is no risk. Diarrhoea does not contain the HIV, unless it has blood in. And it would still have to get inside your bloodstream. Use gloves or cover your hands for hygiene anyway.</td>
</tr>
<tr>
<td>How long can you live if you get HIV/AIDS?</td>
<td>This depends on many things. If you are healthy and can eat well and have lots of love and support, you can live for many years. If you can get access to antiretroviral drugs and take them consistently, you can live many years. Remember that HIV and AIDS are different things. With HIV you have the virus but you are healthy. With AIDS, it means your immune system is low and you may have a number of infections (or “opportunistic infections”). It is important to treat these infections. Just remember finding out you are HIV positive is NOT a death sentence.</td>
</tr>
<tr>
<td>Is it true that condoms are not really safe?</td>
<td>If used properly, condoms offer 98% protection against HIV (and pregnancy). The virus cannot pass through a condom. Make sure your condoms are not out of date, and store them in a cool place. Don’t use Vaseline or oil on them as this can make them break. Never use more than one condom at a time! Some churches teach that condoms are not safe but this is not true.</td>
</tr>
<tr>
<td>Is there any cure for AIDS?</td>
<td>There is no “cure” but there are more and more treatments available which slow down the impact of the HIV. These are called anti-retroviral drugs or ART. They are widely available in Western countries, and people there no longer think that HIV means you will die. ART is becoming more available, cheaper and easier to access in Africa. There are some big campaigns which are trying to force governments and drug companies to make ART available to everyone. Ask your local clinic for information.</td>
</tr>
</tbody>
</table>
Objectives

By the end of this activity participants will be able to:
- articulate their fears about HIV/AIDS
- explain how these fears affect how they respond to PLHA.

Suggested process

Step 1: Card storming - fears about AIDS?
- Hand out cards.
- Ask participants to think about their three greatest fears about AIDS.
- Ask them to record each fear on a card and tape on the wall.
- Cluster common points.

Some possible answers
- Getting infected
- Dying slowly and painfully
- Blame, shame, isolation by others
- Shame – people talking about us
- The unknown
- Infecting my partner
- Divorce or separation
- Losing friends
- Losing jobs
- Neglect
- A friend getting sick and dying
- Loss of hope
- No chance to have children
- Helplessness
- Having to take responsibility if a parent dies
- Getting HIV from nursing someone else
- Leaving children as orphans
- Burden to my parents if I get sick
- Getting pregnant and then discovering I am HIV positive
- Being scared for my teenage children
Step 2: Sharing in pairs – how do fears affect our attitudes towards PLHA?

- Divide into pairs.
- Ask pairs to discuss "How do your fears affect the way you feel about and treat PLHA?"

Step 3: Conclusion

Use Notes for facilitators to guide your conclusion. Summarise the feelings expressed, and thank participants for their honesty, emphasising that issues like stigma have to be dealt with on the value, belief, and emotional level.

It takes courage to admit one’s feelings, especially when one knows that they are not necessarily rational or politically correct! Thank participants about being open about their fears and how they affect their attitudes to PLHA. Explain that these fears are natural and we all have them (they are rooted in basic fears of contagion), but that the fears are a major part of stigma. Because of these fears, we instinctively put PLHA at a distance and this is one form of stigma.

Fear feed stigma. Fear can stop us being rational and finding out the correct information; or it can lead us to accept incorrect information: thinking that blood will ‘exchange’ and get into our bodies; or thinking that HIV is on top of the skin like a skin disease/fungus and can jump inside; or thinking that a PLHA who is preparing food may have blood on his hands, the blood may get into the food and people may eat the food and get HIV.
Feared activities include:

- Accidents - PLHA getting cut; coming into contact with PLHA's blood
- Contact with PLHA's blood when I am helping to wash him at home
- While preparing food, PLHA cuts herself by accident - blood gets on food
- Helping to lift the PLHA when s/he has deep sores
- Carrying the body of a dead PLHA to the church or cemetery
- Eating a communal meal in a common pot with PLHA family member
- PLHA holding or playing with children
- Sharing toilets - virus from inside the toilet
- Shaking hands - HIV in sweat
- Sharing utensils - spoons, cups hold HIV from infected person
- Kissing when the PLHA has cuts in his mouth or on his lips.

**Objectives**

By the end of this activity participants will be able to:

- name their fears in relation to specific forms of nonsexual contact with PLHA
- reflect on why they think that HIV can be transmitted through those activities, and replace these fears with fact.

**Suggested process**

**Step 1: Card storm - fears about non-sexual (casual) contact**

- Divide participants into pairs and ask: “What fears do you think people have about non-sexual casual contact with PLHA at home or at work?”
- Ask pairs to write single points on cards and tape them on the wall.
- Our aim is to find out indirectly what participants’ own fears are.
- Then ask participants to prioritise: “What do you think are the biggest fears?”
Step 2: Role-play

- Then ask each pair to select one of the high priority fears and make a role-play to show how people stigmatise because of fear of this form of contact.
- Ask pairs to present their plays. After each role play ask:
  - “What happened?”
  - “Why do people think those forms of contact will lead to HIV infection?”

Step 3: Processing and reflection

- Take each example and review why people think that HIV can be transmitted in that way.
- Then review the fact sheet and discuss why HIV cannot be transmitted through casual contact.
- Hand out and discuss the fact sheet on Quality, Quantity, and Route of transmission (QQR).

Example from a workshop

**Shaking hands**

Friend avoids shaking hands by pulling his hand away. Why? HIV will spread through body contact, so I don’t want to touch him.

**Kissing on cheek**

Person avoids kiss on cheek, using as an excuse “I can’t hug you because I have a bad/cold.” Why? PLHA may have cuts on the face and I may contract the virus through kissing the cheek.

**Injured person**

Person avoids contact with injured person who he suspects is HIV positive. Why? Blood might get on me if I touch him and I would get HIV.

**Sharing toilet**

PLHA goes to toilet. Another person avoids using the toilet after him. Fears that HIV can be transmitted through the toilet seat.

**Sharing utensils**

PLHA is a family member. Puts plates into a separate pile and writes the name on each plate so that they can be kept separately. Fears that he will be affected through “germs” left on the plate.
QQR
Quality, quantity, route

For HIV transmission to take place, the quality of the virus must be strong, a large quantity must be present and there must be a route of transmission.

Quality
For transmission to take place, the quality of the virus must be strong. HIV cannot survive outside the human body — it starts to die as soon as it is exposed to the air. If it is exposed to heat (for example if someone bleeds into a cooking pot) it will die. HIV does not live on the surface of the skin — it lives inside the body. The only place the virus can survive outside the body is in a vacuum (like a syringe) where it is not exposed to air.

Quantity
For transmission to take place, there must be enough quantity of the virus to pose a risk. HIV is found in large quantities in blood, semen and vaginal fluids and breast milk. It is not found in sweat or tears. It is found in tiny amounts in saliva, vomit, faeces and urine but not enough for there to be any risk of transmission, unless blood is present.

Route of transmission
For HIV transmission to take place, the virus must get inside your bloodstream. Our body is a closed system. HIV cannot pass through unbroken skin or even broken skin very easily. If you cut yourself, the blood flows outwards, away from the bloodstream. If you touch someone else’s cut, blood will not swim into your bloodstream!

Common sense and everyday hygiene mean that many concerns that people worry about would not really happen in everyday life. For example you wouldn’t share a toothbrush if it was covered in blood; you would wash if you cut yourself; you would wear gloves or cover your hands if you were cleaning up someone’s diarrhoea.

Using “QQR” you can see why HIV cannot be transmitted by:

- kissing
- hugging
- mosquitoes
- sharing cups and plates
- shaking hands
- giving blood
- sharing toilets
- using the same washing water
- going to school together.
Activity 14

Fears about caring for PLHA at home

Objectives
By the end of this activity participants will be able to:
• identify the places in the home where they fear non-sexual contact with PLHA
• explore ways to deal with these fears.

Suggested process

Step 1: Household mapping - fear and stigma in the household
• Divide the participants into groups.
• Ask participants to make a drawing of a typical house in their community on a flipchart sheet.
• Mark on the drawing “points in the house where people might be scared of getting HIV through non-sexual contact with PLHA and this leads them to stigmatise (e.g. isolate) PLHA”.

Step 2: Report back
• Ask each group to present their drawing and explain why each area that they have marked makes them scared and results in stigma.

Step 3: Smaller group work or whole group discussion
• Either do this as a whole group discussion, or divide participants into the same groups. Ask each group to identify what for them is the biggest fear or concern about casual contact in the home and then explore:
  • Why do people think that this activity may lead to HIV infection?
  • How do these fears lead to stigma?
  • What are the facts which counter this fear or knowledge gap?

Possible points of fear and stigma in the household

Bathroom
• Fear of getting HIV while helping to wash/clean PLHA.
• Uses these facilities alone – fear of sharing of facilities.

Backroom
• Told to stay in the backroom away from visitors.
• This area is prevented from getting visitors.
• Family prevents their children from playing with PLHA.
• No sharing of blankets and clothing.
• Given separate plate and utensils and asked to eat here alone.
• Left out of family discussions and decision making.

Kitchen
• Prevented from cooking for the family or himself.
• Fear of accidents/cuts while cutting meat – fear of HIV transmission through blood.
• Family eats together without PLHA – no sharing of food.

Main bedroom
• No sharing of blankets.

Sitting room
• Minimal contact with visitors – kept in hiding.
**Objective**

By the end of this activity participants will be able to:

- have a clearer understanding of the practical realities of living with HIV and AIDS.

**Suggested process**

**Step 1: Card storm - myths**

- Divide participants into pairs and hand out cards.
- Ask pairs to write on cards all the things they have heard about the lives of PLHA after they have learned they are HIV-positive – myths, misconceptions, do’s and don’ts.
- Cluster common points and review the list.
- Explore the thinking behind the myths and misconceptions, and the effect the myths/misconceptions have on PLHA. Clarify any questions and uncertainties.

**Step 2: Disclosure – personal story of someone living with HIV**

- Invite a PLHA to come and talk to the group about their own experience – and answer group questions.
- Ask the PLHA to address some of the myths identified in Step 1.

**Step 3: Case study - life goes on**

- Divide participants into groups and hand out a copy of the case study.
- Ask groups to discuss and make a list of things they learned from the case study.

**Step 4: Group discussion**

- Get feedback from each group, identifying key learnings from this session.
Dorothy is 28 years old. Three years ago she was tested for HIV. She was a member of one of the evangelical churches, which had planned a mass wedding ceremony for its members. All those taking part had to take a test. After her test, Dorothy was simply told that she would not be taking part. She was given no counselling or support. She only guessed that she was positive.

Dorothy did not tell anyone for two months. She stopped going to church and felt very alone. Then she asked one of her close friends for advice. Her friend suggested that she go to a Counselling Centre to check the result. She offered to go with her. Dorothy took the test again, but this time talked for a long time to a counsellor. The test came back positive. Dorothy continued to see the counsellor, and eventually told her auntie whom she stays with.

Dorothy joined a skills-training scheme for people living with HIV and learned tailoring skills. Two years later she is running a successful tailoring business. She has married and is expecting her first baby. In her spare time, Dorothy gives talks to schools and workplaces about HIV and AIDS.
Objective
By the end of this activity participants will be able to:
• describe a number of beliefs which affect people’s attitudes towards HIV/AIDS, and see how these contribute to stigmatisation.

Suggested process

Step 1: Card storm – beliefs about HIV and AIDS
• Divide participants into pairs (or small groups) and ask pairs to brainstorm beliefs about HIV and AIDS.

Step 2: Task groups – understanding why
• In the same groups (or pairs):
  ▪ Ask each group to select one of the beliefs and try to explain it.
  ▪ Where does this belief come from?
  ▪ What are some of the reasons or thinking behind the belief?

Examples of popular beliefs
• Condoms transmit HIV.
• Using contraceptives such as the pill or loop can prevent a woman from getting HIV.
• HIV is caused by witchcraft.
• The partner who falls sick first is the person who got infected with HIV first – who “brought HIV into the family”.
• Sex with a virgin/young girl cleanses you of HIV.
• Every time you have sex with another person your viral load goes down.
• If one partner is HIV positive, the other must also be HIV positive.
Factors affecting beliefs

- Day-to-day experience and survival learning
- Commonsense understanding of other illnesses
- Teachings of the family, clan, tribe, church
- Ideas from our peers
- Facts learned at school
- Media messages
- Popular beliefs and sayings
- Level of trust in AIDS educators or health workers.

Reasons why people may not trust factual information provided on AIDS

- Educators give contradictory, confusing, or incomplete information
- Audience may not believe educator because of own beliefs, life experience, knowledge

Traditional beliefs which make people distrust facts on HIV/AIDS

- Faith groups – no sex before marriage
- Religious groups – virus is the result of sin
- White people brought AIDS to Africa
- HIV is in the condom
- God is punishing you, so there is no cure
- Muslims don’t get HIV.

Step 3: Card storm - facts we don't believe

- In the same groups/pairs discuss:
  - What do you know already about how HIV is transmitted?
  - Which of those facts do you misbelieve and why?
  - Who gives you information on AIDS? Do you trust people who give you information on AIDS? Do you trust their information? If not why not?
- Probe for traditional beliefs which would make people distrust what they get through AIDS educators or health workers.
Many diseases are associated with shame and blame. Because HIV is sexually transmitted it is heavily associated with sex and ‘bad behaviour’ on the part of the affected individuals. In the stigma research study many people reported that they believed that people living with HIV get it through sexual activity that goes against the social norms or religious teachings.

The link between sex, religion and stigma is also crucial where there is strong belief that HIV is a punishment from God. This section aims to tackle the difficult subjects of sex and morality in our daily lives and explore these issues in relation to HIV-related stigma.

**Activity 17**

**Objective**

By the end of this activity participants will be able to:

- recognise that all people are at risk of getting HIV, so there is no point stigmatising those who already have HIV.

**Suggested process**

- Facilitate the game described below.
- Then discuss, “What does the game mean?”

**Game: In the river, on the bank**

Ask players to stand in a line all facing same direction. Then explain the game:

Where you are standing is the bank. When I say, “In the river”, you should take one step forward. If, however, I say “On the river”, you should not move.

When I then say, “On the bank”, you should take one step back to the starting point “On the bank”. If, however, I say “In the bank”, you should not move. If anyone makes a mistake, they will be eliminated from the game.

Start the game. Give the commands quickly. If anyone makes a mistake, ask them to leave the game. After a few minutes, stop and debrief.
Note that everyone laughed when the first person made a mistake. Ask the person who made the mistake, “How did that make you feel?” (stupid, embarrassed, angry, stigmatised, the laughter made me feel bad! …)

Then explain that this game shows us that “We are all in the same boat”. There is no separation between ‘us and them’. We are all facing and living with this epidemic together. We are all affected – we have all taken risks at one time in our lives and many of us still do and we all have family members and friends who have died of AIDS. Lots of people like to laugh at, blame and judge others, but one day they may also ‘fall into the river’ – and others will laugh at them. Remember: HIV affects everyone.

All of us are at risk of getting HIV so there is no point in stigmatising or blaming those who are already affected. We could join them any day!

### Activity 18

#### Things people say

**Objectives**

By the end of this activity participants will be able to:

- identify labels used by people to stigmatise PLHA and other stigmatised groups
- see that these words hurt.

**Suggested process**

**Step 1: Warm up – switching chairs game**

- Set up chairs beforehand in a circle or square around the walls of the room.
- Allocate roles to each person going round the circle – “PLHA, sex worker, teenage girl, gay man, street child, widow”.
- Continue until everyone has been assigned a role.
- Then explain how the game works:

  I am the caller and I do not have a chair. When I call out two roles, “PLHA” and “sex workers,” all the “PLHA” and “sex workers” have to stand up and run to find a new chair. I will try to grab a chair. The person left without a chair becomes the caller – and the game continues. The caller may also shout “revolution” – and when this happens, everyone has to stand up and run to find a new chair.
- Then shout: “PLHA and sex workers” and get the “PLHA” and “sex workers” to run to a new chair. This starts the game.
- In the debriefing session afterwards, ask: “How did it feel to be called a PLHA or sex worker?”

**Step 2: Rotational brainstorm – Things that people say about...**

- Divide into six groups based on the roles assigned for the game, all the sex workers together, all the street kids in one group, etc. Ask each group to go to its flipchart station. Hand out markers and ask each group to write on the flipchart all the things people say about those in the group.” After two minutes, shout “Change!” and ask groups to rotate. Continue until groups have contributed to all five flipcharts and end up back at their original list.
Some examples of things people say about PLHA


Sex workers


Teenage girls


Gay men


Street kids


Widows


---

**Step 3: Report back - gallery review**

- Walk as a group around the room, looking briefly at each of the flipcharts.
- At each flipchart ask:
  - How do you, “the orphans” (PLHA, etc.), feel if you are called these names? (Ask those who were assigned this label to react to these names.)
  - In what situations do these comments hurt the most?
  - What are the judgements or assumptions behind some of these labels?

**Step 4: Group work - images of PLHA and impact**

Review the lists of characteristics (see above). Ask groups to discuss:

- If these images of PLHA are commonly believed, what are the consequences for PLHA?
- What are the effects of these images?
- If the effects are negative, what can we do to help change these effects?

**Step 5: Group discussion – the effect of what we say**

Issue the handout entitled “The effect of what we say” and discuss.

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“We are not victims, we are not patients, and we are not sufferers. These names are both derogatory and disempowering. We are people living with HIV. We laugh, we cry, we dance, we sing, we play, we argue, we pay tax, we are parents, and children. We belong to families. We are all in communities. Above all these things we are part of human nature. That is the second challenge: destigmatising ourselves and HIV/AIDS.”

Thanduxolo Doro, speaking at the First National Summit for People Living with HIV/AIDS, South Africa, October 2002. Source: SafAIDS.
## The effect of what we say

<table>
<thead>
<tr>
<th>Image</th>
<th>Effects/Impact</th>
<th>How to change</th>
</tr>
</thead>
<tbody>
<tr>
<td>Promiscuous. Sinners. Foolish. Careless/reckless.</td>
<td>Judged, blamed, and condemned by society.</td>
<td>Advocate to others that we are “all in the same boat” — that we all put ourselves at risk at times in our lives.</td>
</tr>
<tr>
<td>Useless. No longer productive. Waiting to die. Burden.</td>
<td>Treated as no longer able to contribute.</td>
<td>Educate society that PLHA can contribute. Empower PLHA to lead full, active lives. Create opportunities for PLHA to use talents.</td>
</tr>
<tr>
<td>Dangerous: they can infect other people through touch.</td>
<td>Isolated and excluded and “quarantined”.</td>
<td>Educate people about HIV transmission so they stop fearing casual contact with PLHA.</td>
</tr>
</tbody>
</table>
Objectives

By the end of this activity participants will be able to:

- explain the meaning and give examples of double standards in their lives, and how this is yet another contributing factor to stigma
- explain what can be done to reduce double standards in our communities.

Suggested process

Step 1: Card storm - introduction

- Ask the group to brainstorm the meaning of the words ‘double standards’.
- Divide into pairs and ask pairs to write on cards
  - “What are some examples of double standards that we see around us?”
- Stick cards on wall and ask one of the participants to read through and summarise.
- We stigmatise others for ‘promiscuous’ behaviour, which we are doing ourselves.
- We tell others to “Abstain, Be faithful and Condomise” and then go out and have unsafe sex with someone else’s spouse.
- Pastor who preaches about sex and sin and then has an affair with his parishioner.
- The extended family advises a man to divorce his wife if she is HIV positive, but if the husband is HIV positive, they expect the wife to look after her husband.

Step 2: Reflection

Ask participants to sit on their own and think of a time in their lives when they didn’t “practise what they preach”. After 3 minutes discuss in the group why is there often a big gap between what we say and what we do.
**Activity 20**

**Judging characters**

**Objective**

By the end of this activity participants will be able to:

- identify the effects of stigma on different players and institutions.

**Suggested process**

**Step 1: Character cards – selection**

Randomly give out the character cards. In pairs, discuss the lifestyle of your character with your partner:

- What do you do for a living?
- Your perceived HIV risk for this person and why.

**Step 2: Sharing – introduction of characters**

Ask each participant to introduce their character – what they do and their perceived health risk – and then put the picture under one of the risk categories (high risk, low risk, no risk).

**Step 3: Changes**

Invite other participants to make any changes and explain why.

**Step 4: Group discussion**

- What did we learn from this exercise?
- How does the community perceive or judge high-risk people? How do we stereotype people? What words do they use? What are the attitudes behind the words?
- What assumptions do we make about people?
- How do we judge/misjudge people? How do we resist judging people?
- Outline the difference between high-risk groups and high risk behaviour.
- How do we tackle stigmatisation with vulnerable groups?

**Materials**

- Prepare character cards, e.g. farmer, soldier, sex worker, teacher, housewife, wealthy businessman, policeman, 18-year-old domestic worker, 20-year-old student, 15-year-old school boy, 14-year-old orphan, informal settlement single-parent unemployed mother of four children, church minister.
- Allocate three categories along the wall – high risk, low risk, no risk.

**See Section 7**

Additional information:

- 7.9 Language and stigma

**Stigmatisation involves:**

- **Judging or blaming** people.
- The judging is based on assumptions about people’s sexual behaviour.
- As humans we often believe or assume the WORST about other people.
- We assume that certain categories of people because of their occupation are at risk: sex workers, truck drivers, soldiers, or mobile businessmen.
- **We are all at risk** – so we should stop judging others.
- HIV is not limited to groups or occupations – it is in every community.

(Source: Adapted by Dr. Gad Kilonzo from The Fleet of Hope (Bernard Joinet and Theodore Mugolola, 1994)
**Step 5: Story and card storming - judging others**

Read out the story below and ask participants to write down their immediate thoughts, feelings and gut reactions on cards. Tape all the cards on the wall and ask participants to read them.

**Story**

Thembi is a nurse in a rural hospital – a lot of her work involves treating PLHA and doing health promotion. She is married to Siboniso, a teacher in the same community, and they have three children. Siboniso has other girlfriends whom Thembi knows about, but she feels powerless to challenge him – they are no longer having sex. She meets a very attractive man with whom she has been having a secret affair. One day she accidentally pricks herself with a needle from an HIV-positive patient and she has an HIV test before considering PEP. She discovers she is already HIV positive.

**Discussion questions**

- Do we judge people ‘who should know better’ (counsellors, nurses, doctors, etc.) more harshly?
- Research about stigma found that nurses were more stigmatised if they got HIV and often wanted to hide their status for as long as possible. Why do you think this is?

**Step 6: Reflection - judging ourselves**

Ask participants to spend 10 minutes alone and reflect about:

- What have you done in your life that is culturally unacceptable?
- What judgements others could make against you? How would they make you feel?
- Ask participants to pair up with someone they feel comfortable with. Discuss how it felt to do the reflection (NOT the ‘unacceptable behaviour’, but the feelings).
- Option: Come into a large group for sharing.

**Step 7: Summarise, emphasising the following:**

- We are all capable of misjudging people based on their occupation, dress, age or gender.
- We make assumptions about people – and this is a source of stigma. Example: a barmaid is assumed to be sexually active because she works in a bar but this assumption may be wrong.
- We have all done things in our lives, which others would judge badly.
Activity 21

Breaking the ‘sex’ ice

Objectives

By the end of this activity participants will be able to:

- talk more openly about sex and their feelings about sex and sin
- recognise that the view that “sex = sin” is one of the roots of stigma.

Suggested process

Step 1: Card storm - breaking the "sex" ice 1 (images of sex)

Put up the word ‘sex’ on a card at the centre of the wall. Hand out cards and markers to participants and ask them to write the first things they think of when they hear the word ‘sex’ and tape on the wall around the central card. Ask: “What does this tell us about how people think about sex?”

Examples: Sin, love, intimacy, immoral, forbidden, fun.

Step 2: Gender group discussion - breaking the ‘sex’ ice 2 (Why do women or men have sex?)

Divide into same-sex groups. Ask groups to do a quick brainstorm on two questions and record on flipchart:

- Why do women have sex?
- Why do men have sex?

Put up the flipcharts (the women’s lists and the men’s lists alongside each other) and compare the views of women and men.

Discussion questions

- Some of the reasons will be similar, some may be very different. What does this tell us about attitudes to sex?
- How are men and women different?
- Do the answers show any links to sin?
Step 3: Card storm in pairs - good (sinless) sex vs bad (sinful) sex

Hand out cards to pairs and ask them to write examples of the ‘good’ sex and ‘bad’ sex, one example per card. Tape the cards on the wall in two columns beside each other.

Examples

<table>
<thead>
<tr>
<th>Bad (sinful) sex</th>
<th>Good (sinless sex)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sex with sex worker</td>
<td>Sex with one’s spouse</td>
</tr>
<tr>
<td>Sex for pleasure</td>
<td>Sex for procreation</td>
</tr>
<tr>
<td>Sex before you get married</td>
<td>Sex after you get married</td>
</tr>
<tr>
<td>Sex in the bush</td>
<td>Sex in a bed</td>
</tr>
<tr>
<td>Sex any time of the day</td>
<td>Sex at night</td>
</tr>
<tr>
<td>Sex with a condom</td>
<td>Sex without a condom</td>
</tr>
<tr>
<td>Sex with the same sex (gay sex)</td>
<td>Sex with the opposite sex.</td>
</tr>
</tbody>
</table>

Step 4: Summary

Although we are aware of these judgements, many of us do have ‘sinful’ sex, even though we may keep it hidden. Sometimes this links to the ‘double standards’. Sometimes we feel ashamed. Not being able to discuss sex more openly may lead to people taking more risks. These judgments about sex and sin can fuel stigma against PLHA.
Objectives

By the end of this activity participants will be able to:

- see that asking a PLHA "Where did you get it?" can be invasive of their privacy, judging or stigmatising
- analyse why people always ask this question when they meet PLHA
- explain how this question makes PLHA feel
- formulate arguments to counter this type of question when it occurs.

Suggested process

Step 1: Game and song - introduction

Explain that this session will look at why the first thing people always ask a PLHA is “Where did you get it?”

Get the group to make up a song or chant with the words “Where did you get it?” in English or a local language. Ask participants to help you.

Pass an object around the circle. When the leader claps, the person holding the object at that time has to step into the centre of the circle. The whole group points their fingers at him/her and chants 3 times, “Where did you get it?” The person in the centre responds to the same beat as the chant with their answer “I got it from my ………...” (e.g. boyfriend, lover, husband, sugar-daddy, a sex worker)

Step 2: Group discussion - why do we ask this question?

- How did you feel when asked this question with everyone pointing fingers?
- Why do we ask this question: “Where did you get it?”
- Does the answer make a difference to how we respond to that person?
- Highlight the following:
  - This question is judging – we want to know how people have “sinned”.
  - The question makes PLHA feel bad or condemned.
  - Maybe it reassures us if we find out that the person got it by doing something that we have not done!

Step 3: Stop-start drama - How to counter this response?

“How can we counter this stigmatising behaviour when it occurs in a social situation?” Act it out using a few actors in the circle. Discuss after each drama and invite others to take over the roles and try out different ways of challenging this behaviour.
Activity 23

Carrying condoms carries stigma

Objectives
By the end of this activity participants will be able to:

- understand how carrying condoms carries stigma
- think about different ways to challenge this form of stigma when talking about HIV/AIDS.

Suggested process

Step 1: Card storm or group brainstorm – why are condoms stigmatised?
Begin the activity and ask if anyone has a condom on them as you need it for the activity. There will be laughter and embarrassment. A participant may come forward – note the group’s reaction. Tape a condom pack on the wall. Ask: “Why do condoms carry stigma?” Do this as a whole group activity and write responses on a flipchart, or divide the group into pairs and ask pairs to write their points on cards and tape the cards on the wall. Discuss.

Step 2: Role play – assess condom use
Divide the group into small groups and hand out the role-play scenarios below. Ask participants to prepare a role-play to show the whole group.

Use ‘Stop-start drama’ to explore the issues at a deeper level. Develop additional scenarios which are more appropriate to the group.
Step 3: Summary

Summarise by emphasising the following:

- Condoms are associated with sex, and sex with sin, judgement, morality, and this goes a long way to explain the link between sex and stigma.

- We need to change people’s perceptions, and challenge the stigma linked to condoms. Rather, condoms = responsibility and mutual respect.

- Close off with the following story:

We had all met the girl my son was going out with. When he was packing to go to university, he accidentally dropped a packet of condoms out of his bag in front of me. He seemed embarrassed, but I just picked them up and handed them back to him. I told him I was glad he was practising safe sex. (Because of my job, I have taught him about gender issues and sex education and condoms.) I felt proud of him.

Scenarios

- A mother asks her son to borrow some money. As he brings out his wallet, a packet of condoms falls out.

- A father asks his daughter to borrow some money. As she brings out her purse, she drops a packet of condoms.

- Girlfriend and boyfriend are talking about having sex for the first time. The girl brings out a packet of condoms.

- A group of girl friends chatting together at home. One is very religious. One brings out a packet of condoms.

- Husband and wife have recently tested HIV positive. They discuss their future. The husband brings out a packet of condoms.

- Husband and wife are about to make love – they have been having unprotected sex for years. The wife is worried about her husband’s unfaithfulness, and suggests to her husband that they use a condom.

Discussion question

- How can we challenge the stigma around condoms?

- How can we show support for the idea that they show someone is being responsible?

Viva condoms, viva shared responsibility and respect! Viva!
**Objectives**

By the end of this activity participants will be able to:

- discuss and explore HIV stigma in relation to gender
- develop ways of looking at perceptions of risk behaviour in relation to gender
- explain the factors that contribute to women being more stigmatised than men.

**Suggested process**

**Step 1: Blame continuum – who is to blame?**

Hand out one card to each participant. Ask each participant to describe his/her character and place the card on the continuum:

- Who is the character? What does s/he do?
- Where would this person be on the blame continuum (ranging from most likely to least likely to bring HIV into the family)?

**Step 2: Group discussion**

- Why are the cards placed where they are?
- What makes someone more likely to be blamed?
- How does the blame link to gender?
- Are women blamed more than men?

**Step 3: Whole group or small group brainstorming – attitudes towards different groups**

- Divide into small groups. Ask participants to brainstorm all the words/labels/insults used by people to describe the different groups.
- Facilitator to note feedback on a flipchart and discuss:
  - What are the feelings behind these names?
  - How do these judgments link to attitudes and beliefs about men/women and sex?
  - How do these judgements contribute to stigmatisation?
Theme 6:
Activities for PLHA-only workshops

Activity 25

**Stigma scale**

**Objectives**
By the end of this activity participants will be able to:

- assess their level of internalised stigma
- share their experiences of stigma
- discuss and identify their own journey of living with HIV and how it has impacted on their lives
- share and discuss how they see themselves and how they think others see them because of their HIV status
- explore ways to address their own internalised stigma.

**Suggested process**
Hand out the copies of the stigma scale. Ask participants to fill them out and be as honest as possible. After they have filled them out ask them to find a partner in the room to share some of their experiences or what they have scored. Give the pairs ten (10 minutes) to share and them come back to plenary to discuss how people are feeling and find ways to overcome internalised stigma.

This stigma scale has been provided as a tool for PHLAs to explore internalised stigma.

**Internalised** = make attitudes or behaviour part of one’s nature by learning or unconscious absorption

It is not a scientific tool and will not measure your ‘precise level of internal stigma’. But it can be used for you to identify your own personal issues, areas in which you are maybe more vulnerable than others, strengths and aspects of yourself on which you could work.

The above activity is only one suggestion of how the tool can be used. Use it creatively and flexibly: it can be adapted, simplified, used for self-exploration, or group discussion.

Dip into the questions, and select those which make sense for you.

Use it as a way to identify and understand the broad range of issues involved in dealing with stigma.
**HIV stigma scale**

This study asks about some of the social and emotional aspects of having HIV. For most of the questions, just circle the letters or numbers that go with your answer. There are no right or wrong answers. Feel free to write in comments as you go through the questions.

This first set of questions asks about some of your experiences, feelings, and opinions as to how people with HIV feel and how they are treated. Please do your best to answer each question. For each item, circle your answer: Strongly disagree (SD), disagree (D), agree (A), or strongly agree (SA)

<table>
<thead>
<tr>
<th>Question</th>
<th>Strongly disagree</th>
<th>Disagree</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. In many years of my life, no one knows that I have HIV.</td>
<td>SD</td>
<td>D</td>
<td>A</td>
<td>SA</td>
</tr>
<tr>
<td>2. I feel guilty because I have HIV.</td>
<td>SD</td>
<td>D</td>
<td>A</td>
<td>SA</td>
</tr>
<tr>
<td>3. People’s attitudes about HIV make me feel worse about myself.</td>
<td>SD</td>
<td>D</td>
<td>A</td>
<td>SA</td>
</tr>
<tr>
<td>4. Telling someone I have HIV is risky.</td>
<td>SD</td>
<td>D</td>
<td>A</td>
<td>SA</td>
</tr>
<tr>
<td>5. People with HIV lose their jobs when their employers find out.</td>
<td>SD</td>
<td>D</td>
<td>A</td>
<td>SA</td>
</tr>
<tr>
<td>6. I work hard to keep my HIV a secret.</td>
<td>SD</td>
<td>D</td>
<td>A</td>
<td>SA</td>
</tr>
<tr>
<td>7. I feel I am not as good a person as others because I have HIV.</td>
<td>SD</td>
<td>D</td>
<td>A</td>
<td>SA</td>
</tr>
<tr>
<td>8. I never feel ashamed of having HIV.</td>
<td>SD</td>
<td>D</td>
<td>A</td>
<td>SA</td>
</tr>
<tr>
<td>9. People with HIV are treated as outcasts.</td>
<td>SD</td>
<td>D</td>
<td>A</td>
<td>SA</td>
</tr>
<tr>
<td>10. Most people believe that a person who has HIV is dirty.</td>
<td>SD</td>
<td>D</td>
<td>A</td>
<td>SA</td>
</tr>
<tr>
<td>11. It is easier to avoid new friendships than worry about telling someone that I have HIV.</td>
<td>SD</td>
<td>D</td>
<td>A</td>
<td>SA</td>
</tr>
<tr>
<td>12. Having HIV makes me feel unclean.</td>
<td>SD</td>
<td>D</td>
<td>A</td>
<td>SA</td>
</tr>
<tr>
<td>13. Since learning I have HIV, I feel set apart and isolated from the rest of the world.</td>
<td>SD</td>
<td>D</td>
<td>A</td>
<td>SA</td>
</tr>
<tr>
<td>14. Most people think that a person with HIV is disgusting.</td>
<td>SD</td>
<td>D</td>
<td>A</td>
<td>SA</td>
</tr>
<tr>
<td>15. Having HIV makes me feel I’m a bad person.</td>
<td>SD</td>
<td>D</td>
<td>A</td>
<td>SA</td>
</tr>
<tr>
<td>16. Most people with HIV are rejected when others find out.</td>
<td>SD</td>
<td>D</td>
<td>A</td>
<td>SA</td>
</tr>
<tr>
<td>17. I am very careful who I tell that I have HIV.</td>
<td>SD</td>
<td>D</td>
<td>A</td>
<td>SA</td>
</tr>
<tr>
<td>18. Some people who know I have HIV have grown distant.</td>
<td>SD</td>
<td>D</td>
<td>A</td>
<td>SA</td>
</tr>
<tr>
<td>19. Since learning I have HIV I worry about people discriminating against me.</td>
<td>SD</td>
<td>D</td>
<td>A</td>
<td>SA</td>
</tr>
<tr>
<td>20. Most people are uncomfortable around someone with HIV.</td>
<td>SD</td>
<td>D</td>
<td>A</td>
<td>SA</td>
</tr>
<tr>
<td>21. I never feel the need to hide the fact that I have HIV.</td>
<td>SD</td>
<td>D</td>
<td>A</td>
<td>SA</td>
</tr>
<tr>
<td>22. I worry that people may judge me when they learn that I have HIV.</td>
<td>SD</td>
<td>D</td>
<td>A</td>
<td>SA</td>
</tr>
<tr>
<td>23. Having HIV in my blood is disgusting to me.</td>
<td>SD</td>
<td>D</td>
<td>A</td>
<td>SA</td>
</tr>
</tbody>
</table>
Many of the times in this section assumes that you have told other people that you have HIV, or that others know. This may not be true for you. If the item refers to something that has not actually happened you, please imagine yourself in that situation. Then give the answer (strongly disagree*, disagree, agree, strongly agree*) based on how you think you would feel or how you think others would react to you.

<table>
<thead>
<tr>
<th>Number</th>
<th>Item</th>
<th>Strongly disagree</th>
<th>Disagree</th>
<th>Agree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>24.</td>
<td>I have been hurt by how many people reacted to learning I have HIV.</td>
<td>SD</td>
<td>D</td>
<td>A</td>
<td>SA</td>
</tr>
<tr>
<td>25.</td>
<td>I worry that people who know that I have HIV will tell others.</td>
<td>SD</td>
<td>D</td>
<td>A</td>
<td>SA</td>
</tr>
<tr>
<td>26.</td>
<td>I regret having told some people that I have HIV.</td>
<td>SD</td>
<td>D</td>
<td>A</td>
<td>SA</td>
</tr>
<tr>
<td>27.</td>
<td>As a rule, telling others that I have HIV has been a mistake.</td>
<td>SD</td>
<td>D</td>
<td>A</td>
<td>SA</td>
</tr>
<tr>
<td>28.</td>
<td>Some people avoid touching me once they know that I have HIV.</td>
<td>SD</td>
<td>D</td>
<td>A</td>
<td>SA</td>
</tr>
<tr>
<td>29.</td>
<td>People I care about stopped calling after learning I have HIV.</td>
<td>SD</td>
<td>D</td>
<td>A</td>
<td>SA</td>
</tr>
<tr>
<td>30.</td>
<td>People have told me that having HIV is what I deserve for how I lived my life.</td>
<td>SD</td>
<td>D</td>
<td>A</td>
<td>SA</td>
</tr>
<tr>
<td>31.</td>
<td>Some people close to me are afraid others will reject them if it becomes known that I have HIV.</td>
<td>SD</td>
<td>D</td>
<td>A</td>
<td>SA</td>
</tr>
<tr>
<td>32.</td>
<td>People don't want me around their children once they know I have HIV.</td>
<td>SD</td>
<td>D</td>
<td>A</td>
<td>SA</td>
</tr>
<tr>
<td>33.</td>
<td>People have physical backed away from me when they learn I have HIV.</td>
<td>SD</td>
<td>D</td>
<td>A</td>
<td>SA</td>
</tr>
<tr>
<td>34.</td>
<td>Some people act as though it's my fault I have HIV.</td>
<td>SD</td>
<td>D</td>
<td>A</td>
<td>SA</td>
</tr>
<tr>
<td>35.</td>
<td>I have stopped socialising with some people because of their reactions to my having HIV.</td>
<td>SD</td>
<td>D</td>
<td>A</td>
<td>SA</td>
</tr>
<tr>
<td>36.</td>
<td>I have lost friends by telling them I have HIV.</td>
<td>SD</td>
<td>D</td>
<td>A</td>
<td>SA</td>
</tr>
<tr>
<td>37.</td>
<td>I have told people close to me to keep secret the fact that I have HIV.</td>
<td>SD</td>
<td>D</td>
<td>A</td>
<td>SA</td>
</tr>
<tr>
<td>38.</td>
<td>People who know that I have HIV tend to ignore my good points.</td>
<td>SD</td>
<td>D</td>
<td>A</td>
<td>SA</td>
</tr>
<tr>
<td>39.</td>
<td>People seem afraid of me once they learn I have HIV.</td>
<td>SD</td>
<td>D</td>
<td>A</td>
<td>SA</td>
</tr>
<tr>
<td>40.</td>
<td>When people learn you have HIV, they look for flaws in your character.</td>
<td>SD</td>
<td>D</td>
<td>A</td>
<td>SA</td>
</tr>
</tbody>
</table>

**Scoring for the HIV Stigma Scale and Subscales**

Items are scored as follows: Strongly disagree = 1; Disagree = 2; Agree = 3; Strongly agree = 4

If a subject selects a response in between two options (e.g.: between SD and D), a numerical value midway between the two options would be used (e.g.: 1.5). Two items are reverse-scored: items 8 and 21.

After reversing these two items, each scale or subscale's score is calculated by simple adding up the raw values of the items belonging to that scale or subscale. Subscale designations appear in small print in the far margin of the instrument; it may be desirable to cover or delete those numbers before reproducing the instrument for administration to subjects. Sixteen items belong to more than one subscale, reflecting the inter-correlations of the factor on which the subscales are based.

The range of the possible score depends on the number of items in the scale. For the total HIV Stigma Scale, scores can range from 40 to 160 (1x40 items). For the personalised stigma subscale, scores can range from 18 to 72. For the disclosure subscale, scores can range from 10 to 40. For the negative self-image subscale, scores can range from 13 to 52. For the public attitudes subscale, scores can range from 20 to 80.
Objectives

By the end of this activity participants will be able to:

- be stigma advocates
- plan stigma mitigation in their lives.

Suggested process

Step 1: Group work and discussion – what’s the problem with stigma?

Divide the group into two small groups. Group 1 should discuss “Why is it important to address stigma?” and come up with examples. Group 2 should discuss “What is the impact of internalised stigma on my life?”

- Record all responses on a flipchart paper and then have a discussion.
- Once the groups have completed the discussions have the groups report back in plenary.

Step 2: Group discussion – so what do we do?

- Have a group discussion about what kind of action we can take, using the examples from Step 1. The facilitator should note the suggestions on the flipchart.

An advocate is someone who publicly supports or argues for a certain issue; or argues for a cause on behalf of those who do not have a voice to do so.
Activity 27

Objectives
By the end of this activity participants should be able to:
• apply what they have learned during the workshop in their personal life and at work.

Suggested process

Step 1: Individual reflection: stigma in my life
• Give participants the Developing an action plan handout.

<table>
<thead>
<tr>
<th>Problem</th>
<th>Action step</th>
<th>Resources needed</th>
<th>By whom</th>
<th>By when</th>
</tr>
</thead>
<tbody>
<tr>
<td>Problem # 1</td>
<td>a.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>b.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>c.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Problem # 2</td>
<td>a.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>b.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>c.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Problem # 3</td>
<td>a.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>b.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>c.</td>
<td></td>
<td></td>
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</tr>
</tbody>
</table>

• Ask participants to write their responses to the questions on the worksheet entitled ‘personal life’, ‘professional life’ and ‘workplace’. Remind the participants to answer the questions as honestly as possible. Ask participants to brainstorm and write down any problems they identify and select the three most urgent problems (allow 15 minutes).
Additional workplace-based questions

1. Ask participants to think about all that they have learned during this training and then think about their workplace setting and the degree to which attitudes, policies, procedures, and practices are in line with what they have learned.

2. Are there in-service continuing education activities or staff meetings that address staff attitudes and feelings about HIV/AIDS stigma?

3. Are guidelines for standard precautions and their infection prevention procedures posted in service areas?

4. Are staff’s rights protected in the workplace?

5. Do staff members participate in developing strategies for ensuring safety, dignity, and the rights of all staff members and clients? Are those strategies/activities implemented and monitored?

Step 2: Group discussion: developing an action plan

- Re-convene the large group and ask people to share their responses. Record the 3 personal and 3 workplace problems most commonly cited on flipchart paper.

- Divide into six groups to discuss the action plan (one problem per group), or do this as a whole group discussion. Get examples of action plans from smaller groups.
## Developing an action plan

<table>
<thead>
<tr>
<th>Problem</th>
<th>Action step</th>
<th>Resources needed</th>
<th>By whom</th>
<th>By when</th>
</tr>
</thead>
<tbody>
<tr>
<td>Problem # 1</td>
<td>a.</td>
<td></td>
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<tr>
<td></td>
<td>b.</td>
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<tr>
<td></td>
<td>c.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Problem # 2</td>
<td>a.</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>b.</td>
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<tr>
<td></td>
<td>c.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Problem # 3</td>
<td>a.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>b.</td>
<td></td>
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</tr>
<tr>
<td></td>
<td>c.</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
**Objective**
By the end of this activity participants should be able to:
- describe human rights in general.

**Suggested process**

**Step 1: Small group brainstorm – basic human needs**
Stick up a picture of a baby at the front of the training room. Break the participants up into small groups of 4-5 people. Each group should select one person to report back to the plenary session. Ask the groups to consider what the baby would need to have a full life as a human being. Each group should agree upon a list and these are to be noted on flipchart paper.

**Step 2: Group report backs and discussion – basic human rights**
Allow 15 minutes for groups to present their lists. In order to save time, have one group present their list and thereafter have groups just add to the list, or suggest changes. Once all groups have presented and the list is complete, lead a discussion, asking the following questions:
- Why do you think the baby needs all those items in the lists? What good will these do to the baby?
- Does the baby deserve all these? Why or why not?
- How about you? Do you deserve to have what the group thinks the baby should enjoy? Why or why not?
- Are there other things that adults must have to enjoy a full life? What concepts/ideas do you think can be used to refer to all the things babies and adults need to have in order to lead a full life or to live as human beings?
- What do you think might happen if babies and adults are deprived of these?

**Notes for facilitator**
This is a useful exercise for participants to:
- start thinking about human rights
- identify the participants' level of knowledge of human rights
- highlight the difficulties in agreeing on what should constitute a human right. The exercise could lead into a discussion about the balancing of rights and the drafting of a bill of rights.

The types of rights that should ideally be part of the list include: human dignity, equality, life, freedom and security of the person, privacy, freedom of religion, freedom of expression, freedom of association, freedom of movement and residence, safe and healthy environment, education, housing, health, rights of children, right to information, and the right to language and culture.

During the discussion, ensure that the important points from the section on human rights are highlighted, including what rights are, the characteristics of rights, the categories of rights and where rights come from.
Objective
By the end of this activity participants should be able to:

- describe the dynamics and interrelationship of the categories of human rights, those whose rights have been violated, and duty bearers.

Suggested process

- Divide participants into groups of 4-5 people. Ask groups to choose one person who will report back in the plenary session. Distribute the two handouts.
- Ask each group to answer the following questions:
  - What rights are found in this article? What kinds of rights are these?
  - Who are the victims? Who are the violators? Is the state accountable? In what way is the state accountable?
  - How can these rights be protected?
- On the flipchart, draw the following table and ask groups to follow the format to make it easier for presentation:

<table>
<thead>
<tr>
<th>Specific right</th>
<th>Classification of human right</th>
<th>Victims</th>
<th>Violators</th>
<th>State accountability</th>
<th>Ways of protecting</th>
</tr>
</thead>
<tbody>
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</tbody>
</table>
- Reconvene in plenary and have each group report back on their article.
It is important to determine the literacy level of the participants before embarking on this exercise. If the literacy levels are low, then the same exercise can be done using pictures.

Use this exercise to highlight the section on human rights, including that the state is the primary duty bearer with respect to respecting, protecting, promoting and fulfilling human rights, and what this means. Emphasise that the Bill of Rights also, in spirit, applies horizontally, i.e. between people, and there are some sections in the Bill of Rights that apply equally to ‘everyone’ or ‘all persons’.

This exercise can also highlight that different kinds of rights are interrelated and equal. It is not possible to ensure one category of rights without another. For example, if a woman is sick and cannot access health care, she cannot go out to look for work. She is unable to access social assistance because she cannot go to the local home affairs office without transport money. She does not have an ID book and without that, she cannot apply for a disability grant. She does not have money for food and cannot get better without food. When there is a local government election, she is unable to go to vote because she did not register when it was time to do so, and anyway, she does not have the money for transport to go to the voting station. Thus, several of her human rights are being affected: access to health care, access to social assistance, access to food, and her right to vote.
Simplified version of the Bill of Rights

1. You have the right to equality and freedom from discrimination

The law must treat, protect and benefit everyone equally. No person shall be discriminated against because of his or her race, gender, sex, pregnancy, marital status, ethnic or social origin, colour, sexual orientation, age, disability, religion, conscience, belief, culture, language or birth. Measures designed to protect or advance people in order to achieve equality (such as affirmative action programmes) may be necessary to guarantee this right.

2. Your human dignity will be respected and protected

You have the right to be treated with respect and dignity at all times. No one can insult you because of your race, colour or appearance.

3. You have the right to life

Nobody has the right to deprive you of your life. In South Africa the death penalty has been ruled unacceptable in terms of this right. In some countries this is given a wide meaning and can include the right to basic life necessities such as food, shelter, work and health care.

4. You have the right to freedom of the person and control over your body

You have the right to be free. Your freedom cannot be taken away from you unless the law allows this, for example, if you are arrested on suspicion or sentenced for committing a crime. You cannot be detained without trial, tortured or treated inhumanely. You have the right to make your own decisions concerning reproduction.

5. Servitude and forced labour cannot be inflicted on you

Slavery is forbidden by the Bill of Rights. You cannot be forced to work for anyone against your will or to work without pay.

6. You have the right to privacy

Your home and person are private. No one can search your home or person or interfere with your post and telephone, unless a crime is being investigated and the law governing searches is respected.

7. You have the right to freedom of religion, belief and opinion

You have the right to practise whatever religion you wish without interference. You can belong to any political party of your choice and hold any opinion you wish. You cannot be forced to do something against your conscience or beliefs. This right also provides that traditional law may be recognised in certain areas, provided that it does not conflict with any other fundamental rights.

8. You have the right to freedom of expression

You have the right to say what you like, whether this means speaking out against the government or putting forward a view that is not popular. This also includes freedom for the media, artists and researchers. However, this right does not permit war propaganda or the promotion of hatred or imminent violence.

9. You have the right to freedom of assembly, demonstration and petition

All people are free to attend meetings, demonstrate and present petitions, as long as they do so peacefully and without carrying weapons. A peaceful demonstration cannot be banned.

10. You have the right to freedom of association

You have the right to join any organisation of your choice. Any group of people with a common interest have the right to meet together and constitute themselves as an association or organisation in accordance with the law.
11. You have political rights
You have the right to make your own political choices. You have the right to join the political party of your choice and to participate in its activities, or to form your own party, recruit members and campaign. All citizens have the right to regular, free and fair elections. All adult South Africans have the right to vote in secret and to stand for election.

12. South Africans have citizen’s rights
South African citizens cannot have their citizenship taken away from them without proper reason. Citizens have the right to enter, remain in and leave the country. You have the right to a passport.

13. You have the right to freedom of movement and residence
Everyone has the right to travel freely anywhere in South Africa and to leave the country. All South African citizens can live in any province, town and residential area they choose. However, the authorities do have the right to regulate the informal residential occupation of land.

14. You have the right to freedom of trade, occupation and profession
You have the right to try to make a living anywhere in South Africa and to practise the trade or profession of your choice, although the government can regulate how you practise. (For example, it may require doctors to have certain qualifications.)

15. You have the right to fair labour practices
You have the right to fair labour practices in the workplace. You cannot be unfairly dismissed, paid below the minimum wage in your industry or deprived of leave or sick pay. Workers have the right to join and participate in the activities of a trade union. They also have the right to collective bargaining and to strike. Employers have the right to form employers’ organisations.

16. You have the right to a clean environment
You have the right to an environment that is not harmful to your health or well-being. The state must ensure that pollution is prevented and that rubbish is properly disposed. Cleanups and conservation must be promoted.

17. You have property rights
You have the right to hold property that belongs to you. The state may only take away your property if it is in the public interest to do so, for example for the building of a road or school. Land may also be redistributed to redress injustices arising from past racial discrimination. When property is taken away by the state, the owners must receive just compensation.

18. You have the right to housing
All people have the right to adequate housing. The state must take all reasonable steps to guarantee this right. This right also means that no one can evict people from their homes or demolish dwellings without full respect for the law.

19. You have the right to health care, food, water and social security
All people have the right to sufficient food and water. People who are unable to support themselves have the right to social security. All people have the right to health care, including reproductive health care. Nobody can be refused emergency medical treatment.

20. Children are specially protected by the Bill of Rights
Children under the age of 18 have the right to proper care and security, basic nutrition, shelter, basic health care and social services. They cannot be exploited in the workplace or be allowed to do dangerous or unhealthy work. They have the right to be protected from neglect, abuse and degradation.
21. You have the right to education

Everyone has the right to a basic education. This right includes basic literacy for adults. You have the right to be educated in the official language of your choice, where this can reasonably be done. People also have the right to establish private schools, provided that they do not discriminate on the basis of race and maintain acceptable standards.

22. You have language and cultural rights

You have the right to use the language of your choice. You can participate freely in cultural life by practising whatever customs and traditions you like, provided that you do not violate others’ rights.

23. Cultural, religious and linguistic communities have rights

All people and communities are entitled to enjoy their culture, practise their religion and use their language. They also can organise associations based on their culture, religion or language, provided this does not infringe upon other fundamental rights. Cultural councils have the right to be established and recognised.

24. You have the right to access to information

You have the right to all information held by any state department that you may need to exercise and protect your rights. However, certain information may be withheld on the grounds of state security. Different countries give their countries different amounts of access to government information. The exact meaning of this right may be specified further by Parliament if it passes an Open Democracy bill.

25. You have the right to administrative justice

You have the right to be treated fairly and lawfully by any government official. You are also entitled to be given reasons for administrative decisions. If you believe that an administrative decision was wrong or unreasonable, it can be reviewed by a court of law.

26. You have the right to access to the courts

It is your right to have disputes settled by an independent and impartial court. The courts must serve all South Africans equally and fairly. Courts hear both criminal and civil cases.

27. Detained, arrested and accused persons have rights

No one can be arrested or detained without good reason and proper legal procedures must be followed. Detainees have the right to be informed in a language they understand of the reason for their arrest. Prisoners have the right to be kept in humane conditions and to have access to a lawyer, doctor, religious counsellor and spouse or partner. People arrested must be told of their right to remain silent. Anyone charged with a crime has the right to a fair trial by an impartial court, without ‘unreasonable delay’. Anyone accused of a crime is considered innocent until they are proven guilty in a court.

NOTE: The Bill of Rights provides that rights can be limited under certain circumstances

It is important to note that rights are not absolute. The Bill of Rights provides that they can be limited as long as the limitation is “reasonable and justifiable in an open and democratic society”, taking into account several factors, including the nature of the right, the nature and extent of the limitation, the purpose of the limitation and whether there are less restrictive means that could accomplish the same purpose.
Simplified version of the Universal Declaration of Human Rights

Summary of Preamble

The General Assembly recognises that the inherent dignity and the equal and inalienable rights of all members of the human family is the foundation of freedom, justice and peace in the world, human rights should be protected by the rule of law, friendly relations between nations must be fostered, the peoples of the UN have affirmed their faith in human rights, the dignity and the worth of the human person, the equal rights of men and women and are determined to promote social progress, better standards of life and larger freedom and have promised to promote human rights and a common understanding of these rights.

A summary of the Universal Declaration of Human Rights

1. Everyone is free and we should all be treated in the same way.
2. Everyone is equal despite differences in skin colour, sex, religion, and language, for example.
3. Everyone has the right to life and to live in freedom and safety.
4. No one has the right to treat you as a slave, nor should you make anyone your slave.
5. No one has the right to hurt you or to torture you.
6. Everyone has the right to be treated equally by the law.
7. The law is the same for everyone, and it should be applied in the same way to all.
8. Everyone has the right to ask for legal help when his or her rights are not respected.
9. No one has the right to imprison you unjustly or expel you from your own country.
10. Everyone has the right to a fair and public trial.
11. Everyone should be considered innocent until guilt is proved.
12. Everyone has the right to ask for help if someone tries to harm you, but no one can enter your home, open your letter or bother you or your family without a good reason.
13. Everyone has the right to travel as they wish.
14. Everyone has the right to go to another country and ask for protection if they are being persecuted or are in danger of being persecuted.
15. Everyone has the right to belong to a country. No one has the right to prevent you from belonging to another country if you wish to.
16. Everyone has the right to marry and have a family.
17. Everyone has the right to own property and possessions.
18. Everyone has the right to practise and observe all aspects of their own religion and change their religion if they want to.
19. Everyone has the right to say what he or she think and to give and receive information.
20. Everyone has the right to take part in meetings and to join associations in a peaceful way.
21. Everyone has the right to help choose and take part in the government of his or her country.
22. Everyone has the right to social security and to opportunities to develop their skills.
23. Everyone has the right to work for a fair wage in a safe environment and to join a trade union.
24. Everyone has the right to rest and leisure.
25. Everyone has the right to an adequate standard of living and medical help if they are ill.
26. Everyone has the right to go to school.
27. Everyone has the right to share in his or her community’s cultural life.
28. Everyone must respect the ‘social order’ that is necessary for all these rights to be available.
29. Everyone must respect the rights of others, the community and public property.
30. No one has the right to take away and of the rights in this declaration.
Use this exercise to emphasise the following issues:

- the process of stigmatisation and how this often leads to discrimination
- the belief of ‘innocent’ and ‘deserving’ people living with HIV/AIDS, i.e. that children are innocent, but adults are considered to be deserving, especially those who are homosexual or considered to be ‘too’ sexually active
- how human rights violations create barriers to HIV/AIDS prevention as well as care
- the larger structural human rights violations (for example, poverty and gender), which increase the vulnerability for some groups of people, and
- the right of access to health care and what that means to PLHA.

Objectives

By the end of this activity participants should be able to:

- explain the relationship between human rights and HIV/AIDS
- identify the human rights associated with HIV/AIDS.

Suggested process

Small group work - case studies

Divide the participants into small groups of 4-5 people. Ask that one person from each group be selected for the report back in the plenary session. Provide each group with the handout and assign 2-3 case-studies per group.

Ask participants to discuss the case assigned to the group by answering the following questions:

- What human rights violations, if any, were committed against the individual(s)?
- Where has the state failed in its obligation/duty, resulting in the human rights violation?
- Who else, besides the state, failed in its obligation/duty, resulting in the human rights violation?
- What articles of the UDHR, Bill of Rights and domestic laws are being violated by these acts?
- What practical actions can be taken to remedy and protect the rights of the concerned individuals?
- Reconvene in a plenary session. Have each group read its case study, and report its answers to the questions. Open the floor for questions, clarifications and challenges.
Common scenarios

Case 1
An HIV-positive woman who is involved in ‘transactional sex’ (sex for goods or money) in the township. She was beaten up badly when she requested the money. The police refused to help her when she tried to lay a charge of assault.

Case 2
A mother in a rural village was infected by her HIV-positive husband who was a mine-worker in the city, and who has died. She has been isolated by the community. People avoid her and laugh at her children who cannot afford proper school uniforms. The principal has threatened to send the children home if they do not come properly dressed.

Case 3
A soldier who has been passed over for a promotion in the South African National Defence Force because of his HIV status.

Case 4
A female teacher whose test results were released to the school principal by the doctor.

Case 5
A domestic worker who is sent for a test by her employer and then fired when she tests positive.

Case 6
A young woman who is positive due to being raped three years ago.

Case 7
A young woman who is made pregnant by her teacher, and who has tested positive for HIV.

Case 8
A nursing sister who becomes positive after a needle-stick injury at a hospital.

Case 9
A man who is sentenced to prison for two years for house-breaking and becomes infected while in prison.

Look at the case assigned to your group and answer the following:

- What human rights violations, if any, were committed against the individual(s)?
- Where has the state failed in its obligation/duty, resulting in the human rights violation?
- Who else, besides the state, failed in its obligation/duty, resulting in the human rights violation?
- What articles of the UDHR, Bill of Rights and domestic laws are being violated by these acts?
- What practical actions can be taken to remedy and protect the rights of the concerned individuals?
Activity 31: The rights of the PLHA

Objective
By the end of this activity participants should be able to:
• discuss the human rights of PLHA.

Suggested process
Small group work – what’s in the picture?
Divide up the participants into groups of 6-7. Distribute the pictures to the various groups and ask them to discuss the pictures, considering the following questions:
• Who is the PLHA in this picture? Why is he or she the PLHA?
• What is happening in this picture?
• What right is affected in this picture?
• What is the picture showing about the treatment of PLHA?
• What do PLHA need in order to achieve this right?

This exercise is a way to introduce how human rights impact on people living with HIV or AIDS. They show how PLHA should be treated – with respect, love, allowed to have children, etc. They contrast with the earlier pictures used to demonstrate stigma and discrimination.
What's in the picture?
Theme 8: Activities on advocacy

Common methods for doing advocacy work

Objectives

By the end of this activity participants should be able to:

- describe some of the most common methods for doing advocacy work
- explain how some of the skills that people use in everyday life can be used in advocacy work.

Suggested process

Step 1: Small group discussion – exploring advocacy

- Divide the participants into three groups. Hand out flipchart paper and pens.
- Ask participants to discuss and list ways that they have persuaded community leaders, government officials and government departments to change when an injustice or harmful practice has occurred. Alternatively, depending on the participants, ask them to discuss the advocacy campaign strategy that was used by the Treatment Action Campaign when pressurising the government to provide ART to prevent mother-to-child transmission of HIV.
- After the groups have made their list, ask these same groups to make another list that focuses on methods that they have used to persuade members of their families, friends or neighbours of their point of view on an issue that they have felt strongly about.

Step 2: Whole group report back – using advocacy in our lives

- Reconvene in a plenary session. Ask groups to briefly present their lists.
- Ask the following questions to facilitate discussion:
  - Do the two lists overlap? If so, what does this overlap tell us?
  - How do we decide which method to use?
  - Which methods can be used for HIV-related advocacy work?
  - How can the people directly affected by the advocacy issue be involved in advocacy work? Or how can they give their permission for the advocacy work?

Want to know more about advocacy?

See 3.4 Advocacy.
# Advocacy and related concepts

<table>
<thead>
<tr>
<th>Advocacy</th>
<th>IEC</th>
<th>Community mobilisation</th>
<th>Networking and partnerships</th>
<th>Fundraising and resource mobilisation</th>
<th>Overcoming stigma and discrimination</th>
</tr>
</thead>
<tbody>
<tr>
<td>Policies, implementation of policies, laws and practices</td>
<td>Awareness and behaviour</td>
<td>Capacity of communities to identify and address their problems</td>
<td>Isolation and duplication</td>
<td>Level of resources available for HIV/AIDS work</td>
<td>Level of stigma and discrimination against people living with HIV/AIDS</td>
</tr>
</tbody>
</table>

**What can it change?**

- Policies, implementation of policies, laws and practices
- Awareness and behaviour
- Capacity of communities to identify and address their problems
- Isolation and duplication
- Level of resources available for HIV/AIDS work
- Level of stigma and discrimination against people living with HIV/AIDS

**Target group**

- Decision-makers, leaders, policy-makers, people in positions of influence
- Particular age-group, gender, residents of an area, etc.
- Members of a community
- Individuals or groups who have a similar agenda
- Communities, local councils, government, donors
- People who stigmatise or discriminate

**Does it mainly target people who have influence over others?**

- Yes
- No
- No
- No
- No
- No

**Typical indicators of success**

- Policies, implementation, laws or practices which enable improved HIV/AIDS prevention and care
- Percentage of youth using condoms, changes in attitude to people living with HIV/AIDS
- A community problem is solved, more people attend community meetings
- Members of the network or partnership achieve more than they could if they worked alone
- Farmers give use of building for meetings; members of mosque give alms, donor gives grant
- Fewer workers dismissed because of HIV status, less cases of depression among people living with HIV/AIDS
**Objective**

By the end of this activity participants should be able to:

- participate in advocacy planning.

**Suggested process**

**Step 1: Small group work - human rights problems in our communities**

- Divide the participants into 5 groups. Provide groups with flipchart paper and pens. Tell the groups to identify the five most important human rights problems/issues in their community that are related to HIV and AIDS. Ask groups to write down the five key problems and their reasons for this choice. Allow for 30 minutes to complete this exercise.

**Step 2: Advocacy planning**

- Ask groups to present their five most important issues. The facilitator should note them on a flipchart, and make a tick (✓) each time an issue reoccurs. Get the plenary session to agree on the five most common problems. Allow 30 minutes to complete this exercise.

- Distribute the handout on advocacy framework to guide people in the next part of the exercise. Go through the handout with the group.

- Reconvene back into the five small groups, ensuring that there are five groups in total. Assign one of the five problems identified to each of the groups. Instruct them to develop a simple, realistic and attainable advocacy plan following the basic steps and containing the main elements of an advocacy plan. Allow 1 hour to complete this exercise.

- Reconvene in a plenary session and have each group give a presentation on their advocacy plan.

- After each group has presented, discuss with participants which of the five advocacy campaigns presented can be adopted and implemented by the group present.

How can we make this a reality?
Advocacy framework

1. Select an issue or problem you want to address.

2. Analyse the problem and gather information on the issue/problem.

3. Develop aims and objectives for your advocacy work.

4. Identify your targets.

5. Identify your allies.

6. Identify your resources.

7. Create an action plan using key steps.

8. Implement, monitor and evaluate.
Objective
By the end of this activity participants should be able to:
• engage in stigma advocacy in their sectors.

Suggested process
• Divide the group into groups according to sector (faith, workplace, media, etc.). Ask them to discuss:
  ▪ Why is it important to address stigma in our sector?
  ▪ What is the impact of stigma in our setting?
  ▪ What are we going to do about it?
• Report back in plenary and record all responses on the flipchart paper and discuss.

This activity is designed to mobilise participants into action. You should get participants to take the next step by doing specific planning for their sectors. You can use the action plan above as an example. It does not have to be complicated. A small action can make a big difference.
Theme 9: Gender and stigma

Activity 35

Gender roles and sex

Objectives

By the end of this activity participants should be able to:

- have a basic understanding of gender roles, how these roles marginalise other groups and in many ways perpetuate stigma
- understand the difference between gender roles and sex.

Suggested process

Step 1: Individual reflections - reflections on what gender means

- Ask each person to write on a card or piece of paper, whether they see themselves as man/woman, boy/girl or any other perception they have of themselves and give two reasons why they perceive themselves in that way or as that particular gender.
- Put the perceptions up on the wall for all to see.
- Ask for participants to volunteer their input. Look at similarities, differences and ask for clarification.

Sample of responses

- I am a woman, I can give birth.
- I am a man, I have a penis.
- I am a girl/woman because I wear dresses.
- I am a man, I cannot carry babies.

This session will be a first step to an understanding of gender relations and how these factors pose challenges to both men and women in addressing HIV/AIDS.

The way in which both men and women are able or not able to address HIV/AIDS and many other social issues, including stigma, is influenced by how individuals are socialised.

Explain the difference between sex and gender. Explain how gender roles are a creation of society and that these roles can be challenged and changed over time through a lot of education, but this is a process.
Objective
By the end of this activity participants should be able to:

- understand the importance of having a gendered response to the epidemic.

Suggested process
Small group work or whole group brainstorm – challenges with condom use.
Depending on the size of the group, divide the participants into or four small groups.
Ask groups to list two challenges faced by men and women respectively:

- in using a condom
- taking PMTCT
- making a decision about testing
- deciding to disclose HIV status.

Prepare a welcome note on the flipchart with the date and name of the workshop, using local languages.
Objectives

By the end of this session participants should be able to:

- share personal experiences of working with the media
- identify some of the challenges and successes of working with the media
- identify possible capacity needs and strategies for working effectively with the media.

Suggested process

Individual and group work – experiences with the media

- Ask participants to think about experiences they have had working with the media (print, radio, television):
  - What happened? Was it positive or negative?
  - How did you feel?
  - What impact did it have on you?
- Encourage as many of the participants to share their experiences. The facilitator can share his/her own experience to break the ice.
- Discuss:
  - What could have made the experience different?
  - What skills do you need to empower you to work better with the media?
  - Write the responses on the flipchart dividing them into action, feelings and impact.

If it is appropriate, invite someone in the room to relate a personal experience of working with the media and then discuss this afterwards. This could be in place of the activity above or in addition to the activity.
Objective

By the end of this session participants should be able to:

- gain an insight into how the media works.

Suggested process

Invite a media practitioner to address the group on the following topics:

- What are the different types of media?
- Who own and controls the media?
- Why is it important to be informed about the media?
- Why might the media want to talk to you and why might you want to talk to the media?
  - What could you gain?
  - What could you lose?
- What are the constraints in working with media?
- How do the media work?
  - Newspapers
  - Radio
  - Television
- General tips
- Handling interviews and understanding:
  - Deadlines
  - Newsworthiness
  - Preparing for an interview
  - During an interview
  - Afterwards.

Encourage participants to engage in discussion.
Activity 39

Understanding disclosure

Objectives

By the end of this session participants should be able to:

- share personal experiences of disclosing
- identify some of the challenges and successes of disclosure
- identify possible preparation need for effective disclosure.

Suggested process

Step 1: Individual and group reflection – disclosure and myself

- Ask participants to sit on their own at a distance from other participants. Ask them to think about the first time they disclosed their HIV status.
- Allow participants to think through for about 3 minutes and then ask the following questions:
  - What happened?
  - How did you feel?
  - What impact did it have on you?
  - What impact did it have on others?
- In plenary, ask the group to share their experiences. Explain to participants that they need not share their experiences if they do not feel comfortable doing so. Encourage as many of the participants to share as possible. The facilitator can share their own experience to break the ice (if appropriate).

Write the responses on the flipchart, dividing them into events, feelings and impact.

Step 2: Review of handout

- Give out the handout on understanding disclosure.
- Go through it with the group, relating it to the discussion.
What is disclosure?

- Telling an individual or people that you are living with HIV.

What are the types of disclosure?

- Full disclosure
- Partial disclosure
- Indirect disclosure
- Involuntary disclosure
- Non-disclosure

Full disclosure

- Publicly revealing your HIV status to everyone
- Gradual process
- Family, friends, colleagues
- Media (newsprint, radio and TV)

Partial disclosure

- Telling certain people about your HIV status
- Gradual process
- Includes shared confidentiality
- Spouse, relative, friend, colleague

Indirect disclosure

- Referring to HIV and AIDS through paintings and pictures without referring to yourself
- Often occurs while we try to and accept our own HIV status and prepare for disclosure

Involuntary disclosure

- Someone revealing our HIV status without our knowledge or permission

Non-disclosure

- Do not reveal our HIV status to anyone

Why disclose?

- Payment
- Unemployment

Disclosure

- Takes time to accept a positive HIV diagnosis
- Our feelings about disclosure may change over time
- Challenges with disclosure
- HIV and AIDS knowledge
- Silence and denial
- Media images of people living with HIV or AIDS
- HIV- and AIDS-related discrimination
- HIV and AIDS stigma – external and internal

Personal and public disclosure

- Disclose to people we are close to only
- Families, friends and colleagues
- Disclosing to the community
- Disclosing in the media

Understanding disclosure

Resource pack – To reduce stigma related to HIV and AIDS
Understanding disclosure (continued)

Disclosing to my partner

- Consider:
  - the nature of the relationship, is it generally a good one?
  - partner’s personality: is s/he supportive, caring, respectful, understanding or abusive?
  - partner’s coping style when facing stress
  - partner’s maturity
  - your physical and emotional safety when you decide to disclose
  - external support for both yourself and partner

Checklist for planning your public disclosure or to the media

- WHY would you like to disclose publicly?
- WHAT would you like to say?
- WHO are you saying it to?
- WHEN will you be disclosing?
- WHERE will you be disclosing?

Disclosure in a family context

- Access the reasons why you want to tell your family
- Prepare yourself
- Ask for help
- Think positively
- Let the feelings come through
- Let them know you are in good hands
- Let them deny or accept it in their own way
- Accept their responses and try to move on
- Let them know of your plans to disclose publicly

Disclosure to children

- Consider:
  - the child’s age
  - maturity
  - coping style
- Talk to parents who have disclosed to their children

Understanding disclosure (continued)
Activity

Presentation skills: what makes a good speaker?

Objective

By the end of this activity participants should be able to:

• explain the qualities that speakers need in order to communicate effectively.

Suggested process

• Tell participants that they are now going to move around the room. Place a 2-metre length paper on the floor. Ask for a volunteer to lie down on the paper so that they can draw the outline of the person’s body. Ask another participant to draw around the outline of the person who has volunteered to lie on the paper.

• If participants are too shy to do this or it is inappropriate for the group, draw around your co-facilitator or simply draw a life-size outline of a body.

• Ask participants to think about the qualities that make an effective speaker.

• Ask them to write down each of these qualities on the paper, next to the body part that seems most appropriate. If participants are unsure where to write, give them some guidelines. For example: clear minded – head, appropriate language – mouth, no distracting mannerisms – hands, sound preparation – feet, eye contact – eyes. If at the end of this exercise nobody has done so, write, in the centre of the body, ‘open heart’ and ‘passion’.

• Now ask participants to go and stand next to a quality that they believe they have.

• Discuss where each person is standing and ask participants to say why.

• Ask people to look at the outline again and go and stand next to the quality that they most want to work on for themselves.

• Discuss where each person is standing and ask participants to say why.

• Ask participants what they would mostly like to gain from this training. Write participants’ responses up on a large piece of paper.

• Explain that goal setting is continual process. It is each participant’s choice whether to participate in the learning process. It is up to them to get the most out of the workshop.

• Attach the final product to the wall. Tell people that we will review these goals at the end of the course and set new goals for the future.

Suggested time

20 minutes

Materials

• Two-metre length of paper or sheets taped together and several felt tip pens.

• Koki pens

• Flipchart paper
Activity 41

Structuring talks

Objective
By the end of this activity participants should be able to:
• develop a structured approach to storytelling.

Suggested process
• Introduction: Explain that speaking out openly about living with HIV pushes people’s comfort zone. In order to stretch people’s comfort zone gently we need to make them want to hear our story. It is therefore important to work on common points between the presenter and the audience rather than the differences. People remember stories they can relate to. If people relate to the speaker and see some similarity between that person and their own situation, they will be more interested in listening to what the speaker is saying.

• Explain that the first impressions are very important. People often remember, for example, the mood a person was in when they first met. Consequently, beginnings are important. This is when you build rapport with the audience, make connections with them and establish the benefit of the talk for the listener.
Individual reflections and skills development – my story

- Ask participants to sit alone for a moment and think about what they might say at the beginning of their talk.

- Hand out Worksheet: *Think about your talk and what you might want to say*, on the next page, and ask participants to write down their thoughts in point form.

- As a group share ideas about how to begin a talk.

- Explain that it is wise to try and focus on three major points in their story.

- Ask everybody to write down three major aspects of their story that they want to share.

- Ask them to think about why they made these choices.

- Suggest that it is a good idea to group similar ideas together. For example, when highlighting discrimination issues, talk about all the experiences together, rather than moving away from and back to the same concepts.

- Explain that before one begins a talk one must decide where the story is going to end. There is little use in continuing to talk for the sake of filling in time.

- Once a speaker has discussed the major issues that s/he planned to talk about before arriving at the venue, and then it is best to stop and leave time for questions from the floor.

- The ending should bring together elements of the talk and examine a way forward. For example, the speaker might revisit a major point; such as the help they got from HIV-positive peers, and then provide information about support groups or services available. The speaker may be able to provide different types of information, including details of local contacts.

- Ask everybody to write down the concluding points of their talk.

- In review, ask participants to spend five minutes or so reviewing their overall basics structure and the content of their talk and give each their feedback.

- Distribute Handout: *Speaking and presenting guidelines*, and highlight the main points.
Think about your talk and what you might want to say

1. How will members of the audience rate you?

2. What do you have in common with them? It could be your similar educational backgrounds or upbringing or you might remind them of a neighbour or relative.

3. How will you introduce yourself?

4. What mood will you establish?

5. Will you disclose your status immediately?

6. Where will you begin?
Guideline 1: Use your planning steps and question before we speak
- Why am I speaking?
- Who am I speaking to?
- What do I want to say and what do I want my listeners to do?
- How will I get my message across?
- When and where will I speak?

Guideline 2: Make point-form notes
- Plan and structure your talk by making brief notes of main points.
- Try not to write notes in full sentences.

Guideline 3: Develop your main message
- Focus on developing a clear main message.
- Prepare this message around a limited number of key points, for example: around 3 key points.

Guideline 4: Prepare visuals
- Visuals are part of presentations; they help your audience to ‘see’ what you are saying.
- You should prepare your visuals once you have finalised your content, e.g. pamphlets, handouts, newsprints.

Guideline 5: Break the ice
- What you say or do first is very important. Think of a respectful and inclusive way of greeting listeners.

Guideline 6: Explain your structure
- Briefly tell your audience what you will be covering and when they will get a chance to participate. This helps listeners to know ‘where we are going’ and forces us to try to stick to our structure.

Guideline 7: Highlight the main message
- Imagine you are reading out news headlines before going into detail.
- Let listeners know what your main message is.
- Present your main message around the key points you have developed.

Guideline 8: Be aware of your body language, image and speaking habits
- Practise to develop a positive body language and imagine when you speak – for example: the way you dress, stand, speak and respect people.
- Smile to relax your audience and yourself, even if you are nervous.
- Keep eye contact.
- We also all have speaking habits that are sometimes unaware of until a listener points them to us. These are things we say a lot, to the point that they become a habit which blocks others listening to us, for example we say:
  - Um, er, ah (when we hesitate to think)
  - Okay (before or after points)
  - I mean or like (before points)
  - You know (after points)

Guideline 9: Talk loud enough
- Part of projecting a positive image is talking loud enough for everyone to hear us.
- Try to talk to the person in the back of the hall. This is especially important if there is no sound system to boost your voice.

Guideline 10: Keep sentences short
- Put only one idea in a sentence, let your next thought go into another sentence.
- Keep sentences short and punchy as this is what keeps people listening.

Guideline 11: Repeat to emphasise
- Repeat an important point or say it in another way for emphasis, for example: you can give your listeners a practical example or story.
Guideline 2: Speak actively and personally
- Talk directly to your listeners.
- Use active words: “Positive living can be described as” is passive and harder for listeners to follow than “Positive living is”, which is active.
- Be personal, use words like ‘we’, ‘our’ and ‘my’ whenever you can: “One’s life” is not personal and feels very distant while “When we disclose...” uses personal language.

Guideline 3: Avoid unnecessary and extra words
- Avoid difficult words that are unnecessary – in other words, we do not need to use these words.
- Use shorter or easier everyday words, for example: at this moment in time (now), transpired (happened).
- Cut any other words that do not add to meaning.

Guideline 4: Explain necessary difficult words and abbreviations
- Sometimes we need to use difficult words because our listeners need to know what they mean.
- Always say things in full or say it in full the first time.

Guideline 5: Use gender-sensitive, people-friendly and inclusive language
- Be gender-sensitive by using gender-neutral words (e.g. chair, chairperson) or words referring to men and women (e.g. his/her, their)

Guideline 6: Slow down and finish each point
- Talk at a pace that your audience will be able to follow.
- Slow down when introducing points or difficult words.
- Try not to swallow your words at the end of sentences because you are in a rush. If you feel you are rushing, pause and take a deep breath.
- Finish each sentence or point before moving on to the next point. Don’t leave your audience wondering what’s going on while you wander off into another thought.
- Try to concentrate on finishing each main point you wrote down in your preparation.

Guideline 17: Link your message and points
- Always try to link the end of each part of your talk with the next part.
- You can refer to a point you made or an example you used earlier.

Guideline 18: Check on people and summarise
- Make sure that people are ‘with you’ by pausing or asking a question.
- Remember to keep eye contact with your audience.
- Create one or two spaces in your talk to summarise key issues or questions to help your listeners remember them.
- Try to summarise at least once near the end.
- Use summarising after each section of your talk as a way to ensure that everyone is ‘with you’.

Guideline 19: Know when to end
- Stick to your speaking time.
- Remember: listeners usually concentrate for around 10 minutes – you can stretch this to 15 minutes if you mix up talking with exercises.
- Rather cut less important points, than rush to fit everything in.
- Try to end on a positive note, e.g. a challenge, a call to action, or a question.

Guideline 20: Allow time for questions and discussion
- Always try to leave time for people to ask questions, e.g. to clarify difficult words or issues.
- Build in a discussion time linked to questions.
- If time is short, say that: “Anyone is welcome to chat to me afterwards”.
- Always be patient when replying.
- Be aware of your body language and tone of voice when explaining things that people did not understand.
- Make people feel they can ask questions again or ask a follow-up question.
- Try to recognise what people know when you answer.
Objective

By the end of this activity participants should be able to:

• learn techniques to handle difficult situations with the media.

Suggested process

Step 1: Group brainstorm – difficult situations with the media

Ask participants to think of examples of difficult or awkward situations that speakers may occasionally face with a journalist or audience.

These will include times when they ask questions like:

• When did you get infected with HIV?
• Who infected you?
• Does your partner know that you are HIV positive?
• Brainstorm some reasons for these situations.
• They may harbour prejudices due to the speaker’s race, social status, religious views, etc.

Brainstorm some ways to overcome some of these barriers.

Step 2: Optional role play

Ask for a few volunteers to role-play these situations for 5 minutes, one volunteer would role-play the interviewer and the other the interviewee.
Objectives
By the end of this activity participants should be able to:
• identify inappropriate and appropriate language in the media
• deal more effectively with the media with this information.

Suggested process

Step 1: Small group work – newspaper review
• Divide the group into small groups of 4 or 6 people, depending on how big your group is.
• Hand out newspaper clippings with HIV/AIDS headlines.
• Hand out Worksheet on Media scan on the next page.
• Ask participants to read through the newspaper article and answer questions on the worksheet.

Step 2: Plenary
• In plenary have the groups present their answers discuss these and capture them on flipchart paper.
• Brainstorm ways to challenge these in the media.
Media scan

When you read the articles answer the following:

• Is there a stigmatising portrayal of PLHA and HIV and AIDS?

• Describe the language used.

• Describe the images/pictures used.

• Are the headlines sensational?

• Are there perceptions of them and us (‘othering’)?

Resource pack – To reduce stigma related to HIV and AIDS
Stigmatising language and actions

Objectives

By the end of this activity participants should be able to:

- explore and identify stigmatising and non-stigmatising language and actions
- discuss appropriate language to use in relation to HIV and AIDS and PLHA.

Suggested process

- Divide the group into two or four groups, depending on how big the group is. Ask participants in group 1 to list stigmatising and non-stigmatising words and language used in the community in relation to HIV and AIDS and PLHA.
- The other group is to list stigmatising and non-stigmatising actions towards people living with HIV or AIDS that they observed in the community.
- Have the groups report back in plenary and discuss the issues raised.
- Summarise the session by referring to the indicators for stigma on page 82 and distribute Handout: Guidelines for appropriate use of language in HIV and AIDS, on the next page, going through the main points.
Language used and the images it provokes shape and influence behaviour and attitudes. Our choice of words shows whether we respect or disrespect the people with whom we communicate. In the case of HIV/AIDS, it is particularly important that the language we use is accurate, non-stigmatising, non-judgmental and empowering. Below are some common inappropriate terms associated with HIV/AIDS, highlighting why such terms should be avoided in public usage and suggestions for more appropriate terms that can be used in replacement.

### Guidelines for appropriate use of language in HIV/AIDS

<table>
<thead>
<tr>
<th>Inappropriate language</th>
<th>Why?</th>
<th>Appropriate language</th>
</tr>
</thead>
<tbody>
<tr>
<td>AIDS sufferers</td>
<td>Many people living with HIV are healthy and live positive lifestyles. They should not be portrayed as suffering.</td>
<td>People living with HIV or AIDS (PLHA)</td>
</tr>
<tr>
<td>AIDS victims</td>
<td>Victim implies powerlessness, people living with HIV are not victims.</td>
<td>People living with HIV or AIDS (PLHA)</td>
</tr>
<tr>
<td>AIDS carriers</td>
<td>No one carries AIDS. AIDS is the period when an individual’s immune system is damaged by HIV infection, leaving them vulnerable to opportunistic infections.</td>
<td>People living with HIV or AIDS (PLHA)</td>
</tr>
<tr>
<td>Full-blown AIDS</td>
<td>This term implies there is such a thing as ‘half-blown AIDS’. AIDS is simply AIDS. Referring to a term such as ‘full-blown AIDS’ is an unnecessary exaggeration.</td>
<td>AIDS</td>
</tr>
<tr>
<td>AIDS test</td>
<td>When one is tested, it is the HIV antibodies that are identified, not AIDS. One has an HIV test.</td>
<td>HIV test</td>
</tr>
<tr>
<td>HIV virus</td>
<td>HIV stands for human immunodeficiency virus. Therefore, it is incorrect to refer to it as HIV virus.</td>
<td>HIV</td>
</tr>
<tr>
<td>AIDS orphans</td>
<td>Children who have lost either one or both of their parents to AIDS-related illnesses are orphans. They may or may not be infected with HIV. The term AIDS orphans sets them apart from other orphans, yet the issues influencing their health and well-being are the same. By distinguishing children as AIDS orphans we further perpetuate stigmatisation of and discrimination towards these children.</td>
<td>Children affected by HIV/ AIDS or children infected with HIV in the case of HIV-positive children.</td>
</tr>
<tr>
<td>Innocent/guilty</td>
<td>Using the adjective of ‘innocent’ (i.e. innocent children infected with HIV) implies that there are people who are guilty of infecting them or themselves. Using these adjectives promotes stigma around HIV/AIDS.</td>
<td>Avoid using descriptive adjectives</td>
</tr>
<tr>
<td>Inappropriate language</td>
<td>Why?</td>
<td>Appropriate language</td>
</tr>
<tr>
<td>------------------------</td>
<td>----------------------------------------------------------------------</td>
<td>----------------------</td>
</tr>
<tr>
<td>Catching AIDS</td>
<td>A person is infected with HIV through exchange of blood or semen. People do not catch AIDS. AIDS cannot be caught or transmitted.</td>
<td>Become infected with HIV</td>
</tr>
<tr>
<td>AIDS patient</td>
<td>A patient is someone who is seen by medical personnel in a medical setting (e.g. clinic or hospital). Outside of that setting, the person cannot be referred to as a patient. ‘AIDS patient’ identifies a human being by their medical condition alone, whereas many people living with HIV are normal, healthy people who do not need medical attention at all times.</td>
<td>People living with HIV/AIDS</td>
</tr>
<tr>
<td>Battle/war/fight/time bomb</td>
<td>War metaphors are frequently used to describe the process of HIV prevention. However, it gives people an inaccurate and exaggerated understanding of HIV/AIDS.</td>
<td>Avoid war metaphors</td>
</tr>
<tr>
<td>To die of AIDS</td>
<td>People do not die of AIDS; they die of a disease such as TB or bronchitis from a damaged immune system because of HIV infection. It is more accurate to describe that someone has died of an AIDS-related illness.</td>
<td>Died of an AIDS-related illness</td>
</tr>
<tr>
<td>AIDS disease</td>
<td>AIDS is a syndrome where an individual is vulnerable to a number of diseases due to a damaged immune system. AIDS is not disease.</td>
<td>AIDS</td>
</tr>
<tr>
<td>Scourge/plague</td>
<td>Negative and inaccurate terms for HIV or AIDS.</td>
<td>HIV/AIDS epidemic</td>
</tr>
<tr>
<td>A high-risk person</td>
<td>This phrase causes stigmatisation and discrimination towards individuals or groups. It is not the person that is high risk but the behaviour (such as engaging in unprotected sex).</td>
<td>High-risk behaviour</td>
</tr>
<tr>
<td>Prostitute</td>
<td>‘Prostitute’ does not reflect the fact that sex work is a form of employment for a sex worker, not a way of life.</td>
<td>Sex worker</td>
</tr>
<tr>
<td>Body fluids</td>
<td>Confusion about the body fluids that can transmit HIV is a common cause of fear and misunderstanding about HIV and continues to cause discrimination against PLHA. Always explain which body fluids contain HIV in sufficient concentration to be implicated in HIV transmission (i.e. blood, semen, pre-cum, vaginal fluids and breast milk). HIV cannot be transmitted through body fluids such as saliva, sweat, tears or urine.</td>
<td>Blood, semen, pre-cum, vaginal fluids, breast milk</td>
</tr>
<tr>
<td>Aids or aids</td>
<td>AIDS is an acronym for Acquired Immune Deficiency Syndrome. Using lower case letters is incorrect for acronyms.</td>
<td>AIDS</td>
</tr>
</tbody>
</table>
Objectives

By the end of this activity participants should be able to:
• improve their writing skills
• practise their writing skills.

Suggested process

• Present writing guidelines.
• Ask participants to work on their own. They should write a paragraph or two on a topic of their choice to a local newspaper or magazine using the guidelines.
• Hand out *Effective writing guidelines* on the next page.
• Summarise the session and discuss key points about writing.
• Hand out *A writing assessment sheet* on the page following *Effective writing guidelines.*
Effective writing guidelines

Guideline 1 – Use planning steps and questions before we write

• Why am I writing?
• Who am I writing to?
• What do I want to say?
• How will I get my message across?

Guideline 2 – Make space and time to write

• Give yourself time to write without being distracted by other work or personal things.
• Make the time to proofread your writing and get feedback on your writing before you sent it or copy it for distribution.

Guideline 3 – Develop a rough message and structure

• To guide your writing think about your main message and key points.
• Create a structure in point form.

Guideline 4 – Order your information

• Try to put information in an order that makes sense for your readers. Information should flow like a stream.

Guideline 5 – Use catchy headings

• Each section should have a heading to catch the attention of your readers. Think of this as your own newspaper headlines. Your heading should summarise the message of that section.
• Questions are a sharp way of writing clear and active headings.
• Slogans and statements also make good headings.

Guideline 6 – One theme, one paragraph

• Group your information in paragraphs.
• Limit each paragraph to one theme (group of ideas).
• Try to put the main idea of a paragraph in the first sentence of the paragraph.
Guideline 7 – One idea, one sentence

- Try to write shorter, sharper sentences.
- Keep sentences short, i.e. between 10 and 20 words.
- Limit each sentence to one idea.
- A new idea should go into a new sentence.

Guideline 8 – Cut unnecessary details and words

Guideline 9 – Use everyday words when possible

- Try to cut or replace formal, outdated or foreign words.

Guideline 10 – Explain all necessary difficult words and abbreviations

- Sometime you may need to use a difficult legal or medical word – you must find an easy way of explaining it or give an example of what you mean.
- Remember to spell out abbreviations the first time you use them.

Guideline 11 – Use active voice, not passive voice

- As with speaking, write actively and directly.

Guideline 12 – Use personal language

- Write personally for your readers.
- Identify with them by using personal pronouns like we, us, our, you, your, when possible.
- Use the reader’s name when you are writing to one person.

Guideline 13 – Use verbs, not nouns

- Shorten and sharpen your writing by using verbs instead of longer verbal nouns. These are verbs hidden in longer nouns. For example, take into consideration is a verbal noun and can be replaced with consider or make an application can be replaced with apply.

Guideline 14 – Use short connecting and referral words

- You can cuts lots of extra words by using clear words to connect parts of sentences.
- You can often replace 3 or 4 words with one simple word, for example in order to can be replaced with to or on the grounds that can be replaced with because or in the event of rain can be replaced with if it rains.

Guideline 15 – Use gender-sensitive, people-friendly and inclusive language

- Remember to be positive and sensitive whenever you write.
A writing assessment sheet

**Message**
1. Does my writing have a clear message?
2. Does my message get across to its readers?
3. Do my readers know what to do after reading it?

**Structure**
4. Does my main message come through clearly at the beginning?
5. Did I present information in a clear and flowing order?
6. Are there headings to guide the reader?
7. Are the sentences and paragraphs short enough?

**Style**
8. Is my language easy to understand?
9. Are there any unnecessary details and extra words?
10. Did I explain difficult words in plain language?
11. Did I use more active than passive sentences?
12. Do I ‘identify’ with readers by using personal words?
13. Are verbs used more than nouns?
14. Are there short connecting and clear referral words?
15. Am I gender-sensitive and people-friendly, and did I use examples?

**Layout**
16. Are there clear headings and subheading?
17. Is there a user-friendly numbering system?
18. Did I use visuals effectively?
19. Is there plenty of open space (e.g. margins, lists of points)?
20. Is my typeface and font size easy to read?
Objectives

By the end of this activity participants should be able to:

- be familiar with and begin to use the Siyam’kela media guidelines
- critically analyse their programmes in light of the proposed guidelines
- plan and design a plan of action.

Suggested process

- Present the Guidelines.
- Divide the group into small groups to discuss the following topics:
  - How do we incorporate the guidelines into existing programmes?
  - Should these guidelines be adopted and why?
  - Are these guidelines relevant for our situation?
- Give each group about 10 minutes to discuss and then have a plenary session for feedback.
- Summarise this session and close.

The Siyam’kela media guidelines are available at www.csa.za.org, or alternatively you could work with any other reputable set of guidelines.
6. **Sample curricula for stigma workshops**

<table>
<thead>
<tr>
<th>Section</th>
<th>Title</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>A TWO-DAY STIGMA AND MEDIA RELATIONS WORKSHOP FOR PLHA</td>
<td>180</td>
</tr>
<tr>
<td>2.</td>
<td>HELPING A CHURCH HIV/AIDS COMMITTEE TO UNDERSTAND STIGMA AND PLAN AN INTERVENTION IN THE CHURCH COMMUNITY</td>
<td>182</td>
</tr>
<tr>
<td>3.</td>
<td>TWO-DAY AWARENESS AND PERSONAL GROWTH WORKSHOP ON HIV/AIDS STIGMA</td>
<td>183</td>
</tr>
</tbody>
</table>
Sample curricula for stigma workshops

Here are some examples of the workshops which have previously been developed. They are provided to show the combination of activities which could be used to run workshops with different target groups. These are meant as guidelines only and you should adapt them accordingly.

1. A two-day stigma and media relations workshop for PLHA

Day 1

<table>
<thead>
<tr>
<th>Time</th>
<th>Activity</th>
</tr>
</thead>
<tbody>
<tr>
<td>08h00-08h30</td>
<td>Welcome and introductions</td>
</tr>
<tr>
<td>08h30-09h00</td>
<td>Group contract and expectations</td>
</tr>
<tr>
<td>09h00-09h10</td>
<td>Workshop objectives</td>
</tr>
<tr>
<td>09h10-09h30</td>
<td>Understanding stigma</td>
</tr>
<tr>
<td>09h30-10h00</td>
<td>Personal experiences of stigma (stigmatised)</td>
</tr>
<tr>
<td>10h00-10h30</td>
<td>Personal experiences of stigma (stigmatisers)</td>
</tr>
<tr>
<td>10h30-11h00</td>
<td>Tea/coffee break</td>
</tr>
<tr>
<td>11h00-12h00</td>
<td>Internalised stigma scale</td>
</tr>
<tr>
<td>12h00-13h00</td>
<td>Personal experience with working with the media (Group)</td>
</tr>
<tr>
<td>13h00-14h00</td>
<td>Lunch</td>
</tr>
<tr>
<td>14h00-14h30</td>
<td>Personal experiences of working with the media (Individual – PLHA)</td>
</tr>
<tr>
<td>14h30-15h00</td>
<td>Understanding the media</td>
</tr>
<tr>
<td>15h00-15h30</td>
<td>Tea/coffee break</td>
</tr>
<tr>
<td>15h30-16h00</td>
<td>Understanding disclosure</td>
</tr>
<tr>
<td>16h00-16h30</td>
<td>Evaluation and closure</td>
</tr>
</tbody>
</table>
Day 2

<table>
<thead>
<tr>
<th>Time</th>
<th>Activity</th>
</tr>
</thead>
<tbody>
<tr>
<td>08h00-08h30</td>
<td>Recap of the previous day</td>
</tr>
<tr>
<td>08h30-09h00</td>
<td>Presentation skills – What makes a good speaker</td>
</tr>
<tr>
<td>09h00-09h30</td>
<td>Structuring talks</td>
</tr>
<tr>
<td>09h30-10h00</td>
<td>Handling difficult situations in the media</td>
</tr>
<tr>
<td>10h00-10h30</td>
<td>Tea/coffee break</td>
</tr>
<tr>
<td>10h30-11h30</td>
<td>Media scan</td>
</tr>
<tr>
<td>11h30-12h00</td>
<td>Stigmatising language and actions</td>
</tr>
<tr>
<td>12h00-13h00</td>
<td>Effective writing</td>
</tr>
<tr>
<td>13h00-14h00</td>
<td>Lunch</td>
</tr>
<tr>
<td>14h00-14h30</td>
<td>Guidelines for enhancing the interaction of PLHA with the media</td>
</tr>
<tr>
<td>14h30-15h00</td>
<td>HIV and AIDS stigma advocacy</td>
</tr>
<tr>
<td>15h00-15h30</td>
<td>Tea/coffee break</td>
</tr>
<tr>
<td>15h30-16h30</td>
<td>Developing a personal action plan</td>
</tr>
<tr>
<td>16h30-17h00</td>
<td>Evaluation and closure</td>
</tr>
</tbody>
</table>
2. Helping a church HIV/AIDS committee to understand stigma and plan an intervention in the church community

<table>
<thead>
<tr>
<th>Date</th>
<th>Total hours</th>
<th>Activity</th>
<th>Time allocation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Wednesday: 8 September</td>
<td>3 hrs</td>
<td>Registration and welcome</td>
<td>10m</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Getting to know one another</td>
<td>30m</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Expectations and course objectives</td>
<td>20m</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Background of the training intervention and stigma mitigation</td>
<td>1hr</td>
</tr>
<tr>
<td></td>
<td></td>
<td>An overview of HIV/AIDS in South Africa</td>
<td>1hr</td>
</tr>
<tr>
<td>Saturday: 11 September</td>
<td>8hrs</td>
<td>Transmission of HIV</td>
<td>30m</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Prevention:</td>
<td>2hrs</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• sex (and STIs)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>• blood</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>• mother to baby</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>• general awareness</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>• peer education programmes</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>• personal skills approach</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>• vaccines</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Treatment:</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>• signs and symptoms</td>
<td>30m</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• OIs</td>
<td>1hr</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• TB</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>• ARVs</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>• prophylaxis</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>• adherence</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Living positively</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>VCT, counselling, support groups</td>
<td></td>
</tr>
<tr>
<td>Wednesday: 15 September</td>
<td>3hrs</td>
<td>Understanding HIV/AIDS stigma</td>
<td>30m</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• What is HIV/AIDS stigma?</td>
<td>1hr</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Personal experience of stigma</td>
<td>15m</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Present a case scenario and discuss</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Why is it important to address stigma?</td>
<td>45m</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Support for stigma interventions</td>
<td>30m</td>
</tr>
<tr>
<td>Saturday: 18 September</td>
<td>8hrs</td>
<td>Presenting findings from research across South Africa in FBOs</td>
<td>1hr</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Exploring stigma manifestations in this church: through preaching, using scriptures, pastoral services, groups in the church, etc.</td>
<td>2hrs</td>
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<tr>
<td></td>
<td></td>
<td>Do a selection of activities 18 – 25</td>
<td>4hrs</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Present indicators of stigma</td>
<td>30m</td>
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<tr>
<td></td>
<td></td>
<td>Presentation and discussion of guidelines of stigma mitigation, including policy guidelines</td>
<td>1hr</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Discuss examples of stigma work in other FBOs</td>
<td>1hr</td>
</tr>
<tr>
<td>Wednesday: 29 September</td>
<td>3hrs</td>
<td>Understanding HIV/AIDS discrimination and legal recourse in South Africa</td>
<td></td>
</tr>
<tr>
<td>Wednesday: 6 October</td>
<td>3 hrs</td>
<td>Introduction to project management</td>
<td></td>
</tr>
<tr>
<td>Saturday: 9 October</td>
<td>8 hrs</td>
<td>Project management and community mobilisation</td>
<td></td>
</tr>
<tr>
<td>Wednesday: 13 October</td>
<td>3 hrs</td>
<td>How to run and plan a participatory workshop</td>
<td></td>
</tr>
<tr>
<td>Saturday: 16 October</td>
<td>8 hrs</td>
<td>How to run and plan a participatory workshop</td>
<td></td>
</tr>
<tr>
<td>Wednesday: 20 October</td>
<td>3 hrs</td>
<td>How to run and plan a participatory workshop</td>
<td></td>
</tr>
<tr>
<td>Saturday: 24 October</td>
<td>8 hrs</td>
<td>Plan and discuss the stigma interventions for the church community</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Closure, evaluation and way forward</td>
<td></td>
</tr>
</tbody>
</table>
3. **Two-day awareness and personal growth workshop on HIV/AIDS stigma**

**Target:** Clinic nurses

**Aim:** To raise awareness of stigma and explore tools to address HIV/AIDS stigma in our personal and professional lives, in light of the municipality’s HIV/AIDS policy framework

**Objectives:**
- To gain understanding of HIV/AIDS stigma
- To understand how stigma impacts on our personal and professional lives
- To share personal experiences with stigma
- To challenge beliefs and attitudes
- To understand the policy framework of the municipality
- To explore and discuss practical suggestions and strategies for stigma mitigation in the workplace.

**Two-day personal growth workshop outline:**

### Day 1

<table>
<thead>
<tr>
<th>Time</th>
<th>Activity</th>
</tr>
</thead>
<tbody>
<tr>
<td>08h30 - 10h00:</td>
<td>Welcome, introductions, expectations, ground rules</td>
</tr>
<tr>
<td>10h00 - 10h30:</td>
<td>Tea</td>
</tr>
<tr>
<td>10h30 - 12h30:</td>
<td>What is stigma?</td>
</tr>
<tr>
<td>12h30 - 13h30:</td>
<td>Lunch</td>
</tr>
<tr>
<td>13h30 - 14h00:</td>
<td>Personal experiences of stigma</td>
</tr>
<tr>
<td>14h00 - 15h00:</td>
<td>Exploring own beliefs and attitudes about HIV and AIDS</td>
</tr>
<tr>
<td>15h00 - 15h15:</td>
<td>Tea</td>
</tr>
<tr>
<td>15h00 - 16h00:</td>
<td>Impact of HIV stigma on our personal and professional lives</td>
</tr>
<tr>
<td>16h00 - 16h30:</td>
<td>Reflections and closure</td>
</tr>
</tbody>
</table>

### Day 2

<table>
<thead>
<tr>
<th>Time</th>
<th>Activity</th>
</tr>
</thead>
<tbody>
<tr>
<td>08h30 - 09h00:</td>
<td>Review of day 1</td>
</tr>
<tr>
<td>09h00 - 09h30:</td>
<td>Stigma in the workplace</td>
</tr>
<tr>
<td>09h30 - 10h30:</td>
<td>Municipality HIV/AIDS policy and workplace programme</td>
</tr>
<tr>
<td>10h30 - 11h00:</td>
<td>Tea</td>
</tr>
<tr>
<td>11h00 - 12h00:</td>
<td>Presentation of stigma mitigation guidelines</td>
</tr>
<tr>
<td>12h00 - 13h00:</td>
<td>Lunch</td>
</tr>
<tr>
<td>13h00 - 14h00:</td>
<td>Stigma mitigation strategies (group work/discussion)</td>
</tr>
<tr>
<td>14h00 - 15h00:</td>
<td>Development of an action plan (programme action plan)</td>
</tr>
<tr>
<td>15h00 - 16h00:</td>
<td>Evaluation and closure</td>
</tr>
</tbody>
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7. Want to know more? Additional information

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<td>7.13 SIMPLIFIED VERSION OF THE BILL OF RIGHTS</td>
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<td>7.14 SIMPLIFIED VERSION OF THE UNIVERSAL DECLARATION OF HUMAN RIGHTS</td>
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<td>7.15 ORGANISATIONS TO ASSIST WITH HUMAN RIGHTS VIOLATIONS</td>
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7.1 HIV/AIDS and human rights – international guidelines


The Guidelines focus on three crucial areas:

- increasing the capacity of governments for multi-sectoral coordination and accountability
- widespread reform of laws and legal support services, with a focus on anti-discrimination, protection of public health, and improvements in the status of women, children and marginalised groups, and
- support and increased private sector and community participation to respond ethically and effectively to HIV/AIDS.

The twelve guidelines are as follows:

- encourage states to adopt a multi-sectoral approach through an effective national framework
- enable community organisations to carry out activities in the field of ethics, human rights and law. The guidelines support consulting widely with such organisations in drafting all HIV policies
- review and reform public health laws to adequately address HIV/AIDS
- review and reform criminal laws and correctional systems to ensure that they are consistent with international human rights obligations and address HIV/AIDS without targeting vulnerable groups
- enact or strengthen anti-discrimination laws to protect vulnerable groups. It is important to ensure privacy, confidentiality and ethics in research involving human subjects
- enact legislation to provide for the regulation of HIV-related goods, services and information in order to ensure widespread availability of quality prevention measures and services, adequate HIV prevention and care information, and safe and effective medication at an affordable price. The guidelines say it is important to ensure that all persons on a sustained and equal basis have access to quality goods, services and information for HIV/AIDS prevention, treatment, care and support, including anti-retroviral and other safe and effective medicines, diagnostics, and related technologies for the treatment of HIV/AIDS and related opportunistic infections
- implement and support legal support services to educate people affected by HIV/AIDS about their rights, develop expertise on HIV-related legal issues and use means other than courts, such as human rights commissions, to protect the rights of people affected by HIV/AIDS
- promote an enabling and prejudice-free environment for women, children and other vulnerable groups. Both states and communities are to play a role in achieving this
- promote the distribution of creative education, training and media programmes designed to change attitudes of discrimination and stigmatisation around HIV/AIDS
- translate human rights principles into codes of conduct with accompanying mechanisms to implement and enforce these codes
- ensure that states have monitoring and enforcement mechanisms to guarantee and protect HIV-related human rights
- share experiences concerning HIV-related human rights issues at an international level and through UN agencies such as UNAIDS.

1 The International Guidelines are available at http://www.ohchr.org/eng/issues/health/hiv/guidelines.htm

Want to know more? Additional information
The Health Professions Council of South Africa (HPCSA) is a body that was established to control the training, registration and conduct of doctors, dentists, psychologists and other health professionals. The HPCSA has replaced the South African Medical and Dental Council (SAMDC).

In 1994, the SAMDC issued ethical guidelines on the treatment and management of people living with HIV and AIDS. In July 2001, the HPCSA revised and updated the SAMDC guidelines. The HPCSA stresses the importance of keeping a patient’s HIV status confidential. Similarly, the South African Nursing Council (SANC), to which all nurses have to belong, has ethical guidelines emphasising the importance of a patient’s right to confidentiality.

While all health professionals must belong to the HPCSA, the doctors’ voluntary association is known as the South African Medical Association (SAMA). SAMA has also issued guidelines stressing the importance of maintaining patient confidentiality.

A health care worker cannot disclose a patient’s status even to another health care worker unless consent has been obtained first, even if more than one health care worker in the hospital is treating the patient. However, it is advised, in order to get proper medical attention, that the patient disclose his/her status to all health professionals involved in his/her care. (This does not mean disclosing one’s status to everyone in the hospital, only to those that are directly involved in providing treatment to him/her.)

The circumstances in which a health care worker can provide information about a patient to another person are when:

- the patient has agreed to it
- the patient is a child, and the child’s parents or guardian have agreed to it, and
- the patient is deceased, and the patient’s next-of-kin have agreed to it.

There is no duty on a health care worker to inform family members or caregivers of a person’s status. To disclose to another health care worker, the health care worker must first:

- carefully consider the decision
- explain the decision to the patient, and accept full responsibility for his/her decision to disclose.²

A very controversial area has been the issue of disclosure of status to the sexual partner of the patient. The health care worker should first ensure that the patient has counselling on the advantages of telling his/her partner. Should the patient still decide not to disclose, the health care worker should follow certain steps before disclosing to the partner. These include:

- more counselling, including from someone else
- informing the patient that the health care worker has a duty to disclose his/her status to sexual partners who are at risk of infection
- informing the patient that in this case, the health care worker may have to breach confidentiality, and give the patient an opportunity to disclose his/her status himself/herself, and
- make a decision as to whether it is really necessary to disclose the status and breach the confidentiality.

To assist in making this decision, the following conditions must be met:

- the sexual partner must be clearly known and identifiable – in other words, a specific person
- the sexual partner is at risk of being infected with HIV by his/her partner, who has refused to inform him/her of his/her status or to engage in safer sexual practices
- the person has been counselled on the need to inform his/her sexual partner or to have safer sex
- the health care worker has informed the person of the duty to protect his/her sexual partners, and
- the health care worker has warned the person that if he/she does not inform his/her sexual partner or have safer sex, he/she will have to breach confidentiality.

This is a complicated issue as there is the potential for a health care worker to be sued if he/she should have disclosed to a sexual partner and did not do so.

Increasingly, there is a move away from the notion of keeping HIV status secret towards promoting safe disclosure with the assistance of a supportive and non-judgemental counsellor who adopts an enabling approach to disclosure.

A person is entitled to confidentiality about his/her HIV status at work. This means that a health care worker cannot disclose to an employer without the employee’s consent, and that the human resources department or any other department, if aware of the status of an employee, must keep the status confidential.

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² HPCSA Guidelines
7.3 Informed consent

Section 12(2) of the Constitution states that people have the right to bodily and psychological integrity, which means that a person must be free to consent to all medical treatment, and has the right to refuse medical treatment.

Consent involves both information and permission. A person must be provided with all relevant information before he/she is examined, treated, tested, given medicine or operated on. He/she must provide his/her express permission to undergo the treatment or test either orally or in writing.

People have the right to refuse medical treatment and testing. They should not be forced or tricked to consent or treatment.

All adults who have legal capacity and are of sound mind are able to give consent. Mentally ill patients may require assistance to give consent or others may be able to give consent for them. Couples must consent to treatment individually, meaning that one partner cannot consent for the other. Both must provide their own consent.

For children, the Child Care Act (No.74 of 1983) makes it clear that children who are 14 years or older can give consent to medical treatment, such as asking for an HIV test or treatment for an STI, and asking for contraceptives. The Choice on Termination of Pregnancy Act (No. 92 of 1996) allows a girl of any age to consent to a termination of pregnancy. Other surgical operations require children to be 18 years old and over to give consent.

In terms of HIV testing, the HPCSA ethical guidelines say health care workers should not do an HIV test without obtaining informed consent from a person (see previous section). This principle is also reinforced in the National Policy on Testing for HIV from the Department of Health, published in 2000. Thus a person must know what the test is, why it is being done and what the result will mean. A person cannot be coerced or tricked into going for a test. The same is true for HIV vaccine trials, and will also hold true for ART treatment.

The requirements for informed consent can be set aside in certain cases, including:

- **Emergencies** - if a person needs emergency treatment to save his/her life, a doctor or hospital does not need to get consent before carrying out the essential treatment. An ‘emergency’ situation only exists when it is a real emergency which makes the treatment necessary; the patient is unaware that he/she needs the treatment because he/she is unconscious; the doctor tries to get consent from the person’s next-of-kin; the treatment is in the best interest of the person; and the treatment does not go against the wishes of the patient, if known. In an emergency, health care workers can only do an HIV test it is necessary to save the person’s life, although there are few, if any, circumstances where this would be the case. Doing an HIV test for the purpose of protecting a health care worker is not permitted.

- **Testing done on blood donations** – all donations of blood must be voluntary according to the law, which means that people cannot be forced to donate blood or paid for donating blood. After blood is donated, it is screened for HIV, hepatitis B and C, and sexually transmitted diseases. If any of these tests are positive, the blood donor is informed of the results.

- **Mentally ill patients** – if a person is unable to give consent due to mental illness, it is possible to get consent from a curator (person appointed to look after the person), spouse, parent, child (if the child is over 21 years old) or sibling. If the person is institutionalised, the medical superintendent can consent in very serious cases if the next-of-kin cannot be found. In terms of HIV testing, the person can only be tested for HIV if this information is necessary for his/her medical treatment.

- **Anonymous and unlinked testing for research purposes** – this is done to get information on how HIV is spreading in the population. HIV testing is allowed in this form only if it is anonymous, meaning that no names are used, and unlinked, meaning that it cannot be traced back to the person who was tested. In this case, informed consent is not required.

- **Needle-stick injury** – where a health care worker has been exposed to a possible risk of HIV infection (such as where they have pricked themselves with a needle that has already been used on a patient) and where a blood sample is already available and the patient refuses to give informed consent to the HIV test, the blood can be tested without the consent of the patient. The patient must be told that his/her blood sample will be tested, but that he/she will not get the test result unless he/she asks for it, but that the result will be made available to the affected health care worker. If the patient wants to know his/her test result, he/she should be given counselling before the results are provided.

Pre-employment testing for HIV is not allowed generally unless the company has an order allowing such testing through the Labour Court. The Employment Equity Act (EEA) No. 55 of 1998 does not allow for HIV testing of job applicants, or existing employees, or before employees are offered a promotion or training. If the employer wants pre-employment testing or testing of employees, the employer must apply for an order from the labour court, and must motivate why pre-employment testing should be a requirement. Without the order, pre-employment testing is illegal. The Act does not cover the South African National Defence Force (SANDF), or employees of the Secret Services and the National Intelligence Agency.

If a person does not fit into one of these categories and an HIV test is performed without first obtaining informed consent, then there has been a human rights violation.
The Batho Pele white paper

All public health employees are guided by the White Paper on Transforming Public Service Delivery (known as the Batho Pele white paper), issued by the Department of Public Service and Administration.

There are eight principles of Batho Pele that apply to all public servants. These are:

- **Consultation**: Citizens should be consulted about the level and quality of the public services they receive and, wherever possible, should be given a choice about the services that are offered.
- **Service standards**: Citizens should be told what level and quality of public services they will receive so that they are aware of what to expect.
- **Access**: All citizens should have equal access to the services to which they are entitled.
- **Courtesy**: Citizens should be treated with courtesy and consideration.
- **Information**: Citizens should be given full, accurate information about the public services they are entitled to receive.
- **Openness and transparency**: Citizens should be told how national and provincial departments are run, how much they cost, and who is in charge.
- **Redress**: If the promised standard of service is not delivered, citizens should be offered an apology, a full explanation and a speedy and effective remedy. Where complaints are made, citizens should receive a sympathetic, positive response.
- **Value for money**: Public services should be provided economically and efficiently in order to give citizens the best possible value for money.

Termination of pregnancy

The law allows for a woman to terminate a pregnancy and lays out the conditions for this to occur.

There are different requirements for the different periods in the pregnancy. A woman has to give informed consent before undergoing a termination of pregnancy. A woman cannot be forced to have an abortion because she is HIV positive but she can choose to do so after having been counselled on the risks involved and making an informed decision. Importantly, a woman does not have to have her husband’s consent or the consent of the father of the foetus before having a termination. A termination cannot be refused by a doctor or health care facility because a woman has not told the father. Girls can also have a termination without the consent or knowledge of their parents or the father of the foetus. While a girl may be advised to discuss the matter with her parents, she cannot be forced to do so or refused the termination if she chooses not to discuss it with them.

In the first 12 weeks a woman does not have to give reasons for wanting the termination. Between 13 and 20 weeks of pregnancy, a woman can have a termination if her doctor says that there is a risk to her health or that of the foetus, if the pregnancy is the result of rape or incest, or if her social and economic circumstances will be affected by the pregnancy. After the 20th week, a woman can have a termination if a doctor, after discussing it with another doctor or midwife, believes that the pregnancy could be dangerous for the woman or could result in a physically deformed or mentally handicapped baby.
The South African Schools Act (No. 8 of 1996) makes education compulsory for children under the age of 15 years; this would also include HIV-positive children. However, there have been cases of children being denied access to crèches and pre-schools due to their HIV status. This is unfair discrimination and can be challenged. The law does not require that a child’s status be disclosed at school.

Families that cannot afford to pay school fees can apply to the school for an exemption from the fees. Depending on the amount that the family earns per year, they may be granted an exemption from paying fees or the fees may be reduced. No one can refuse a child access to school because of an inability to pay school fees, or refuse to allow the family to apply for an exemption. This is clearly against Department of Education policy.

The Child Care Act (No. 7 of 1983) provides children with protection from exploitation and abuse. The law requires those who work with children, such as teachers, social workers and health care workers, to report any suspicion that the child has been ill-treated to the Department of Social Development, Children’s Court, police officer or medical superintendent of a hospital.

The Child Care Act also identifies situations whereby children are ‘in need of care’. Having a parent or caregiver who is living with HIV or AIDS, or the child him/herself living with HIV or AIDS, does not necessarily mean that the child is ‘in need of care’ and requires placement in alternative care. Rather, it depends on the circumstances of the situation. If the parents or caregiver are not able to take care of the child adequately, then this may mean that the child should be placed in alternative care. Usually, removing a child is considered to be a last resort. There are different forms of alternative care, such as placement with another family in foster care, in an institution or in another family for adoption. In order to place a child in an alternative care arrangement, there must be an order from the Children’s Court.

Due to death or illness of their parents, many children are now in foster care relationships with family members or others such as neighbours. A person may foster up to six children at one time. Children are not tested for HIV before being placed with a foster family. However, when a child’s HIV status is already known and the child is under 14 years, this information may be told to the foster family if it is in the child’s best interests, for example, to ensure that the child receives special medical attention. If a child is being fostered, then the foster family can obtain a foster care grant. However, this process usually takes a long time (see below).

The South African Schools Act (No. 84 of 1996) makes education compulsory for children under the age of 15 years; this would also include HIV-positive children. However, there have been cases of children being denied access to crèches and pre-schools due to their HIV status. This is unfair discrimination and can be challenged. The law does not require that a child’s status be disclosed at school.

Families that cannot afford to pay school fees can apply to the school for an exemption from the fees. Depending on the amount that the family earns per year, they may be granted an exemption from paying fees or the fees may be reduced. No one can refuse a child access to school because of an inability to pay school fees, or refuse to allow the family to apply for an exemption. This is clearly against Department of Education policy.

There is a Children’s Rights Bill which is being reviewed by Parliament currently. This Bill would replace various sections of the Child Care Act.
### Disability grants

People living with HIV/AIDS are eligible for a disability grant if certain conditions are met (see below). In addition, the applicant must pass a 'means test'. Currently, the disability grant is approximately R780 per month. The conditions that must be met to qualify for the disability grant include:

- The person must be a South African citizen
- The person must be 18 years or older
- The person has to consult a doctor and the medical report has to show that he/she is unable to support himself/herself. The examining doctor must be a government doctor or district surgeon, and then the Pension Medical Officer must approve the medical report.
- The person must have an incapacity that means he/she is unable to get any kind of employment. The illness or disability must be permanent, or at least be expected to last more than 6 months. The person will lose the grant if he/she becomes healthy enough to work.
- The person’s spouse cannot afford to support him/her and has also passed the ‘means test’. (This is a test that looks at the person’s financial situation: only people who earn less than a certain amount or who are unemployed will be allowed to receive the grant.)
- The person does not live in a government-run institution, e.g. a prison, a psychiatric hospital, an old age home, a care and treatment centre, or a centre for drug dependents.
- The person must not receive any other social grants.

To apply for the grant, a person must go to the nearest Department of Social Development or pension office, with several documents:

- A bar-coded identity book (ID)
- Proof of income or the value of assets (possessions), including the income or assets of one’s spouse
- Proof of marital status
- A letter from one’s doctor, and
- Any other medical records.

The staff at the government office will take the documents and provide the person applying with a form that needs to be filled out by a government doctor. Once this has been completed, the applicant must submit it to the Department of Social Development. The Department will review the application and decide whether or not the person qualifies for a grant. Usually this process can take 3 to 6 months. If a person qualifies for a grant, he/she may get back pay for 3 months on the first payment (this is the 3 months that it should take for the government to process the grant). If the person is too sick to collect the money, he/she can ask someone to collect it on his/her behalf, but will have to complete some forms to say he/she is still alive.

If the grant is refused, the government must provide reasons in writing. A person can appeal against the refusal, providing reasons why the grant should be given. This appeal should be in writing and should reach the Department of Social Development within 3 months of receiving the refusal letter.

The disability grant can be reviewed every year by the government. They can ask a person receiving the grant to have a medical check-up with a particular doctor. If the doctor believes that the person is no longer disabled and can go out to work, then the grant can be stopped. If the grant is stopped for no reason and without warning, then it is important to try to find out why that happened as soon as possible, so an appeal can be sent if it is required.

As the disability grant is for people who are unable to work, a person is not eligible for a grant immediately on becoming HIV positive, especially if he/she is still healthy or not suffering from any major illness. Rather, a person will qualify for the grant when he/she is too ill to work. This is usually when the person’s CD4 count is between 50 and 200, and/or he/she is suffering from a major opportunistic illness that is likely to last longer six months.

In order to qualify for a disability grant on the basis of HIV status, the person will have to disclose the results of his/her HIV test to an officer at the Department of Social Development, and to the doctor who must complete the forms. However, the right to confidentiality still exists, so the doctor or social worker cannot disclose the person’s HIV status.
The social relief from distress grant is available for an emergency situation, usually while waiting for the processing of the disability grant, for up to three months. It is usually in the form of coupons for use at the supermarket. The amount received is deducted from the disability grant, once the applicant starts receiving it.  

Grants to support children

There are three types of grants in place to support children: the child support grant, the foster care grant and the care dependency grant. These grants have been problematic since many people, especially those in the rural areas, have been unable to access the grants due to a lack of the required documentation, the backlog in reviewing and giving grants by the government, and lack of information on how to access the grants.

Child support grant

The child support grant is given to the main caregivers of children under the age of 7 years. This has recently been extended to children up to the age of 14 years. The grant is supposed to support children living in poor households. It is currently R180 per month. To qualify, the household must pass a ‘means test’, which looks at the combined yearly income of the family. The documents required to access the child support grant include:

- the bar-coded ID of the caregiver and his/her spouse, if any
- the bar-coded birth certificate or ID of the child
- proof (such as an affidavit) that the person making the application is the primary caregiver of the child
- proof of marital status, and
- proof of family income.

Since many children, especially in rural areas, do not have birth certificates or ID books, it has been very difficult to access the child support grant. This is being reviewed and addressed by the Department of Social Development. The Department has developed mobile units to go into rural areas to register children, working with the Department of Home Affairs to assist with ID books and birth certificates, and allowing for other ways of registering children. However, the problem is still a serious one.

Foster care grant

A foster care grant is given to the foster parent of a child (see above). A child can only be placed in a foster family by a court. There is no means test for the foster care grant. The documents required for accessing a foster care grant are:

- the bar-coded ID document of the person applying for the foster care grant
- the bar-coded ID or birth certificate of the child
- proof that the child receives no income
- a court order placing the child in the custody of the foster parent, and
- proof that the child is attending school.

There are serious problems with respect to accessing foster grants. Currently, social workers are dealing with a backlog of applications received in 2002. This is due primarily to the increase in the number of children living with foster parents because of the death of their parents. The foster care grant is approximately R560 per month.

Care dependency grant

A care dependency grant assists to provide care for a child who is ill or needs special attention. The child must be living permanently in the care of the person seeking the grant. While children who have HIV or AIDS should qualify for a care dependency grant, very few have been approved. The grant is approximately R780 per month.

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South African Human Rights Commission (SAHRC)

The South African Human Rights Commission (SAHRC) was established by the Constitution, and is governed by the Human Rights Commission Act (No. 54 of 1994). The SAHRC’s mandate is to promote, protect and monitor human rights in South Africa. The SAHRC promotes human rights by:

- educating and training people about human rights and the Bill of Rights
- raising awareness of human rights, the Bill of Rights, and the work of the SAHRC
- making policies on the rights in the Bill of Rights
- providing advice on human rights to all levels of government, and
- working with international human rights bodies (such as the United Nations) to promote human rights.

The SAHRC protects human rights by:

- taking action to correct human rights violations, such as negotiation, mediation, or taking the case to the Commission or to court
- using the media to make people aware of these violations, and
- deciding what investigations to hold about alleged human rights violations, and how these should be handled.

To ensure that human rights are promoted and protected, the SAHRC engages in monitoring of:

- government laws, policies and programmes, to make sure that these do not violate the Bill of Rights (note that each year, the SAHRC requests all government departments to report on what they have done to protect, promote and fulfil their human rights obligations, to make it possible for people to enjoy their rights)
- private actions to ensure that they do not violate human rights in the Bill of Rights.

The SAHRC deals with cases of alleged human rights violations free of charge. A person can complain to the SAHRC if he/she believes that his/her rights have been abused or violated. The Commission does not take on all cases, however. It focuses on serious types of violations (such as discrimination on any of the grounds set out in the equality clause, or violations of human dignity) and may refer cases to the various other structures in place to deal with them (such as the Public Protector or the Commission on Gender Equality – see below).

It is possible to file a complaint with the SAHRC by phoning (011) 484 8300 and asking for assistance in filing a complaint. A staff member of the SAHRC will assist in completing the complaint form.

A complaint form is also available at http://www.sahrc.org.za/complaint_form.htm. The following information is required to complete the form:

- personal details (address, phone number, and other contact details)
- which right has been violated
- details/facts of what happened (such as the date, where, and what happened)
- the names and contact details of witnesses, and
- the names and details of the person(s) who violated the rights, if this is known.

The form should be submitted to the SAHRC by email, fax, post or in person.

Once a complaint has been received at the SAHRC, it usually takes a long time to be processed. It is possible to call to ask for details on what has happened to the complaint.

The Equality Courts

The Equality Courts are established by the The Promotion of Equality and Prevention of Unfair Discrimination Act, 2000 (Act 4 of 2000). Despite the existence of the law for some time, the Equality Courts were only recently established. The first courts began operating on 16 June 200 and as of August 200, 7 cases had been lodged with only seven finalised. There are equality courts in all nine provinces.

The Courts seek to achieve the quick and informal processing of cases, which enables participation by the parties to the proceedings, and also seeks to ensure access to justice to all people. Cases can run concurrently (at the same time) as criminal cases.

The Act allows for cases to be brought before the equality courts that relate to harm suffered due to unfair discrimination, hate speech and/or harassment. The prohibited grounds for discrimination are the same sixteen grounds specified in Section 9 of the Constitution, plus similar ('analogous') grounds that the court rules to share the same demeaning characteristics as the listed grounds. The test for unfairness is detailed in Section 14. It largely codifies the Constitutional Court findings on the right to equality, that is, unfair discrimination is differentiation which:

- impairs or is likely to impair human dignity
- has a negative impact on the complainant
- is perpetuated generally within society which leads to the victim, due to their membership or perceived membership of a group, suffering from patterns of disadvantage
- is systemic in nature
- has no legitimate purpose
- if for a legitimate purpose, did not achieved its purpose
- was carried out despite there being a less restrictive and less disadvantageous means available, and
- the respondent did not take reasonable steps to:
  - address disadvantage arising from or related to one or more of the prohibited grounds, or
  - accommodate diversity.

Conversely, discrimination will be considered fair if it amounts to positive measures for the protection and advancement of previously disadvantaged groups, for example, a sport’s coach selecting team members from historically disadvantaged groups. The court must take into account the context of the contentious event. In determining the context, the presiding officer must seek to understand the overall impact of the discriminatory action in the context of people’s lives. This includes an examination of the history and socio-economic conditions of the individuals and groups concerned, as well as the impact of the impugned provision on social patterns and systemic forms of disadvantage.


The Public Protector

The Public Protector investigates complaints about government officials such as pension pay-out clerks. A complaint about government officials should be sent to the Public Protector who will decide if it is a complaint that requires investigation, try to resolve the complaint, or refer it to someone who can do so.

To make a complaint to the Public Protector, one must submit an affidavit. The affidavit must include:

- details and information about the problem, and
- reasons why the Public Protector should investigate the complaint.

A person can get assistance in drafting an affidavit from a paralegal or from the police. The telephone numbers for the Public Protector are (012) 322 2916 or 0800 112040.

Commission for Gender Equality (CGE)

The Commission for Gender Equality (CGE) investigates and challenges laws, practices and customs that discriminate against people because of their gender. The mandate of the CGE includes:

- educating people about gender equality
- investigating gender-related issues
- resolving disputes, and
- recommending to Parliament and other law-making bodies to introduce new laws or change laws to promote gender equality.

To file a complaint, telephone, fax or post a letter, or visit the CGE offices. The complaint should include as much information as possible. To contact the CGE, contact (011) 403 7182.

Independent Complaints Commission (ICD)

The Independent Complaints Commission (ICD) investigates cases of alleged violations of human rights by the police. To contact the ICD, call (012) 339 1554.
Commission for Conciliation, Mediation and Arbitration (CCMA)

The Commission for Conciliation, Mediation and Arbitration (CCMA) assists people who have been subjected to an unfair labour practice or whose labour rights have been violated. All cases involving employment and discrimination are dealt with by the CCMA. People report their complaints to case management officers, who then refer the case to the Commissioners, if there is merit to the case. The CCMA must first try conciliation, which involves trying to reach a voluntary agreement between the sides in the dispute. They must also try mediation, which involves getting both sides to agree to bring in someone who is independent and who will listen to both sides of the story and then make a decision. If mediation does not work, then the CCMA uses arbitration, which involves bringing in an independent person to hear the case and make a decision. This is different from mediation because the decision is final and binding on everyone involved.

Disputes that cannot be solved at the CCMA can be referred to the Labour Court. However, it is necessary to approach the CCMA before approaching the Labour Court. The CCMA can be contacted at (011) 377 6650.

Legal Aid Board

The Legal Aid Board provides lawyers to people who cannot afford them and who qualify for legal aid. They do this in many different types of cases, including in criminal cases. This Board has offices at all Magistrate’s Courts. The Head Office for the Legal Aid Board can be contacted at (012) 481 2700.

Legal aid clinics

Most universities have legal aid clinics to help people who cannot afford a lawyer. University legal aid clinics usually cover only certain areas of law. Contact the university in the area to determine what areas they cover.

Non-governmental organisations, community-based organisations and paralegals

There are many non-governmental organisations (NGOs), community-based organisations (CBOs) and paralegals in South Africa. They may be able to help or refer to a person or organisation that can assist. For example, the following organisations are helpful in matters dealing with human rights abuses and violations:

- Black Sash: (011) 834 8361
- Lawyers for Human Rights: (012) 320 2943
- Legal Resources Centre: (011) 836 7901

Complaints against medical doctors

To make a complaint against a medical doctor, contact the South African Medical Association (SAMA) and the Health Professions Council of South Africa (HPCSA). SAMA is a professional association of doctors, which doctors can join voluntarily (this means that not all doctors will be a members of SAMA, so it is important to see if the doctor that is being complained about is a member before approaching SAMA for help). Upon receiving a complaint, SAMA will try to mediate between the complainant and the doctor to resolve the dispute. If this is not possible, SAMA must refer the dispute to the HPCSA. SAMA has no powers to discipline its members, but it can expel a member from the association.

To file a complaint about a doctor, put all the facts in a letter and fax or post it to SAMA. It is important to include contact details so that SAMA is able to contact the person who has complained. To contact SAMA, call (012) 481 2000.

The HPCSA is a statutory body that governs health professionals who are members of the HPCSA and it is mandatory for all health care professionals to be a member. The HPCSA has wide powers to discipline members, including the right to suspend members from practising. When the Council receives the complaint, it will investigate it and if necessary, it will hold a formal enquiry. However, there has been controversy about how seriously the HPCSA takes complaints, especially against doctors.

To file a complaint, send an affidavit setting out all of the details of the complaint against the doctor or other medical professional. The HPCSA can be contacted at (012) 338 9300.

Complaints against nurses

All nurses are registered with the South African Nursing Council (SANC), a statutory body. The SANC can discipline its members, investigate complaints, and if necessary, hold a formal enquiry. To file a complaint, send an affidavit including all the important details about the complaint, the nurse and details of the incident. It is possible to contact the SANC on (012) 343 0121.
Civil claims

A civil claim is a claim for money for compensation for damages (harm) that was done. Civil claims can be launched in the following cases:

• where one’s right to confidentiality has been violated, it is possible to launch a civil claim for damages against the health care worker or the hospital/clinic that violated the right to confidentiality

• if one has been assaulted, it is possible to claim damages for pain and suffering, loss of wages and medical costs from the person who assaulted one. A criminal charge can also be laid against that person (see below)

• if someone violates one’s right to privacy and dignity, then a claim can be launched against that person

• if someone says something harmful about one in public, then one can claim damages against the person for the harm caused by the statement(s), and

• a civil claim for pain and suffering is possible when a person has done something that causes one shock, body disfigurement or paralysis, damages one’s health or personality, or cuts short the number of years one is likely to live (e.g. though a serious car accident).

Civil claims will require the services of a lawyer because civil claims involve many complicated legal proceedings. In many cases, there are time limits within which a claim can be launched. For example, for a claim against a health care worker, a claim must be filed within 12 months of the incident (in the case of government hospitals and clinics) or 36 months (in the case of a private clinic or doctor).

To begin a civil claim, make a statement to a paralegal or lawyer. This should be done as soon as possible and include as many details and facts as possible. It is a good idea to have any witnesses also provide a statement. The lawyer makes the statement into an affidavit, and the person who is claiming his/her rights were violated must swear to the validity of the affidavit. The lawyer will write a ‘demand letter’ to the person who violated the rights, outlining the violation that occurred and the damages that were suffered as a result. If the alleged violator does not settle, the case can be taken further to either the Magistrates’ Court or the High Court. Most civil claims are made through the Magistrates’ Court. The Magistrates’ Court will hear claims for up to R100 000.

The High Court can hear any type of civil cases, but usually focuses on cases that are too serious for the Magistrates’ Courts, and any cases where the amount claimed is more than R100 000. The High Court can also hear appeals and reviews against judgments of the Magistrates’ Courts.

Another court that can hear civil cases, and that does not require a lawyer, is the Small Claims Court. It is designed to allow for people to represent themselves and the processes are simpler, less costly, are heard by a Commissioner rather than a Magistrate, and take less time. The Court requires a minimum amount of R50 to cover the costs of the proceedings. However, the Small Claims Court will only hear cases for up to R3 000.

Criminal charges

A person commits a crime if he/she breaks the law. If a crime is committed against a person, he/she can make a criminal case against the person who committed the crime, or the state (the police) can bring a charge against that person. The police can investigate and bring a charge and then the attorneys employed by the government should prosecute the case, if there is enough evidence to do so. For example, criminal charges can be brought in cases where:

• a health care worker takes blood from a patient without his/her consent. This is “assault”, and

• someone seriously harms another person’s dignity and standing in the community, by, for example spreading malicious gossip about him/her. Then the person causing the harm can be charged with a crime called “crimen injuria”.

It is important to remember that although a person can lay a charge, it may not be a good idea for him/her to do so. Deciding whether to lay a charge requires balancing the negatives and positives of the situation. For example, the complainant (the person laying the charge) will have to reveal his/her status, it will take time for the case to be investigated and for the case to go to court and be concluded, and the outcome may not be in his/her favour. On the other hand, it may be an important principle to uphold, despite the outcome, and the complainant may want to ensure that the person who caused the harm does not do the same to other people. The complainant must decide whether to pursue the case.

The police will not charge someone for a crime lightly and will carry out their own evaluation, looking at a number of
factors such as the seriousness of the incident, the importance of deterrence (making sure that others do not do the same thing), and the likelihood of conviction. However, remember that even if the police do not lay charges, it does not mean that the incident did not happen and was not important; rather it means that they decided not to go forward with laying charges for various reasons.

If a person has been a victim of a crime, and the police have either not been informed or have not laid a criminal charge, the following steps are to be followed to lay a criminal charge:

- **Make a statement.** The person must first make a statement to a paralegal or someone else who can take the statement and assist with the case. If possible, the paralegal should take pictures, visit the scene of the incident and also interview other witnesses.

- **Go to a doctor.** If the case involves assault, rape or other injuries, it is important to go to the doctor as soon as possible for a medical check-up.

- **Report to the charge office.** As soon as possible after making the statement, go to the charge office at the nearest police station (the police station that is nearest to where the incident occurred), preferably with the person who took the statement.

- **Make a statement to the police.** The complainant will be asked to make a statement to the police. The police must take the statement, and they cannot refuse to listen or refuse to take the statement. The statement should be the same as that given to the paralegal or person who helped in the first case. The statement will be the basis for what is said under oath at the trial (see step 8), so it is important to be clear and confident of what it contains. One should not sign the statement until one is happy with it, and ask for a copy before leaving the police station. A person has a right to his/her statement.

- **Ask for a police reference number.** The police reference number is the number in the register where the police are supposed to keep a record of all complaints made at the charge office. This is proof that a complaint was made to the police.

- **Ask for the case-docket number.** After the statement is made and the complaint registered, the police are supposed to open a case docket and investigate the criminal charge against the person who committed the crime. It is important to ask for the case-docket number, as this will assist in checking on the progress of the case.

- **Check on the progress of the case.** Based on the case-docket number, it is possible to find out who the investigating officer working on the case is. The investigating officer is the police officer who is in charge of investigating the case. Take note of his/her name and then communicate with him/her regularly on the status of the case. While it may be difficult to contact the investigating officer, a complainant has a right to be kept informed of any new developments and how the investigation is proceeding.

- **The criminal case.** After the investigation is completed, the case docket is handed over to the local office of the Director of Public Prosecutions. The prosecutor will decide whether there is enough evidence to prosecute the person against whom charges were brought by the complainant. If the case goes ahead, the complainant will receive a formal legal notice (a ‘subpoena’) to be in court to give evidence on a particular date and time. On this date, the complainant should go to court early so that the prosecutor can explain what is happening and what kinds of questions he/she will be asked. The complainant has a right to read over his/her statement again before giving evidence.9

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7.9 Language and stigma

(a) Take a historical perspective

(This section is adapted from an article entitled “UQedisizwe – The Finisher of the Nation: Naming and talking about HIV/AIDS in African languages” by Tessa Dowling.)

Language is extremely important in influencing people’s perceptions. In addition languages (and especially African languages) provide a culturally rich resource. There is a strong tradition in African languages of naming, praising and respecting. It is important that we understand the power of these traditions in influencing perceptions.

Naming in African languages is always significant, with most given names having a meaning. The names given to HIV/AIDS are similar to those used when talking about powerful leaders and outstanding personalities – complex, compound names normally heard in praise poetry, in the reciting of genealogies.

Compare the praises of a great fighter, Mqikela Ndayi: USinandile, unqamb’ esililini. (He is a rifle speeding to its target.) (in Opland 1998:06) with this name for AIDS, the great killer: UDubul’ egeqa (He who shoots to kill).

People react emotionally to praise names which invoke respect and, in some instances, fear. HIV/AIDS must be feared and therefore its personification and “praise” names are appropriate.

Interestingly, however, in ordinary discourse and in marketing and educational campaigns, no one has thought to give the condom a praise name. There are no advertisements or posters that refer to the condom as UMsindisi weSizwe (The Saviour of the Nation) or other similar praise names that could so easily be coined.

In fact, not only are condoms not given praise names, they are rather trivialized, likened to everyday, commonplace objects such as jackets (idyasi), gumboots (igambutsi) and baby bags (mokotsla wa bana). Similarly, while there are ways of talking about people living with AIDS, there are no praises for them. There are no names to inspire, to suggest strength and survival in the face of all odds. Rather, a PLHA is someone who has “caught it” (ubhaqile), or who has had “a hot coal fall upon himself or herself” (uwelwe lilahle).

In African languages, Dowling argues, there are two categories for HIV/AIDS that encourage the “victim” view, those being HIV/AIDS as personified killer and HIV/AIDS as taboo. There is yet another category that takes its references from popular culture, and almost pokes fun at the prevalence of the disease, branding it as a game, a ride on an overcrowded train.
(b) **Examine the language of media messages**

Language and information on HIV and AIDS as presented in the media have an important impact on the development and experience of stigma. The media is a powerful tool because of its reach and influence. It can influence people’s opinions, attitudes and behaviour. The media can make messages about HIV and PLHA non-stigmatising. Media professionals can examine and modify the language used in media to ensure that it does not portray HIV and people living with HIV in negative stereotypical ways.

(c) **Provide accurate information**

It is important to provide accurate, up-to-date and complete information. The wrong information can lead to greater stigma. It is also important to present information in ways which are not sensational.

(d) **Do not reinforce misperceptions**

There are many misperceptions about HIV and PLHA. There are also many stereotypes about who gets HIV and the lives led by PLHA. Images and concepts that should be avoided include:

- those focusing on high-risk groups (e.g. truck drivers, sex workers, drug users) instead of on high-risk behaviour (e.g. unprotected sex, sharing syringes)
- images of PLHA as 'promiscuous' and 'immoral', and as a danger to members of the faith community
- images of PLHA 'at death’s door'
- images of PLHA as unable to live fulfilling lives because of their HIV-positive status
- understanding of HIV/AIDS as a 'scourge' or plague
- understanding of some PLHA as innocent, which implies that some PLHA deserve to be infected
- the language of 'us and them'.

HIV/AIDS prevention messages should rather:

- use positive language that is inclusive and sensitive – for example, using the term ‘people living with HIV/AIDS’ instead of ‘AIDS victims’.

Unfortunately the messages which we want to encourage regarding HIV, are sometimes contradictory:

- On the one hand we want to encourage support and caring for those living with HIV and so we may tend to have a negative focus on the difficulties of living with the virus. But on the other hand we want to encourage a message of hope that people living with HIV are able to live fulfilling and productive lives.
- On the one hand we want to encourage the message that HIV is dangerous and that if you do not protect yourself you may become HIV positive with very negative consequences for your life. But on the other hand we want to say that even with HIV, you can live a fulfilling life.

Clearly the messages that are portrayed through the media have to be carefully balanced.
### Guidelines for appropriate use of language in HIV/AIDS

Language used and the images it provokes shape and influence behaviour and attitudes. Our choice of words shows whether we respect or disrespect the people we are communicating with. In the case of HIV/AIDS, it is particularly important that the language we use is accurate, non-stigmatising, non-judgmental and empowering. Below are some common inappropriate terms associated with HIV/AIDS, short discussions on why such terms should be avoided in public usage, and suggestions for more appropriate terms that can be used as a replacement.

<table>
<thead>
<tr>
<th>Inappropriate language</th>
<th>Why?</th>
<th>Appropriate language</th>
</tr>
</thead>
<tbody>
<tr>
<td>Catching AIDS</td>
<td>A person is infected with HIV through exchange of blood or semen. People do not catch AIDS. AIDS cannot be caught or transmitted.</td>
<td>Become infected with HIV</td>
</tr>
<tr>
<td>AIDS patient</td>
<td>A patient is someone who is seen by medical personnel in a medical setting (e.g. clinic or hospital). Outside of that setting, the person cannot be referred to as a patient. ‘AIDS patient’ identifies a human being by their medical condition alone, whereas many people living with HIV are normal, healthy people who do not need medical attention at all times.</td>
<td>People living with HIV/AIDS</td>
</tr>
<tr>
<td>Battle/war/fight/time bomb</td>
<td>War metaphors are frequently used to describe the process of HIV prevention. However, it gives people an inaccurate and exaggerated understanding of HIV/AIDS.</td>
<td>Avoid war metaphors</td>
</tr>
<tr>
<td>To die of AIDS</td>
<td>People do not die of AIDS; they die of a disease such as TB or bronchitis from a damaged immune system because of HIV infection. It is more accurate to describe that someone has died of an AIDS-related illness.</td>
<td>Died of an AIDS-related illness</td>
</tr>
<tr>
<td>AIDS disease</td>
<td>AIDS is a syndrome where an individual is vulnerable to a number of diseases due to a damaged immune system. AIDS is not disease.</td>
<td>AIDS</td>
</tr>
<tr>
<td>Scourge/plague</td>
<td>Negative and inaccurate terms for HIV or AIDS.</td>
<td>HIV/AIDS epidemic</td>
</tr>
<tr>
<td>A high-risk person</td>
<td>This phrase causes stigmatisation and discrimination towards individuals or groups. It is not the person that is high risk but the behaviour (such as engaging in unprotected sex).</td>
<td>High-risk behaviour</td>
</tr>
<tr>
<td>Prostitute</td>
<td>‘Prostitute’ does not reflect the fact that sex work is a form of employment for a sex worker, not a way of life.</td>
<td>Sex worker</td>
</tr>
<tr>
<td>Body fluids</td>
<td>Confusion about the body fluids that can transmit HIV is a common cause of fear and misunderstanding about HIV and continues to cause discrimination against PLHA. Always explain which body fluids contain HIV in sufficient concentration to be implicated in HIV transmission (i.e. blood, semen, pre-cum, vaginal fluids and breast milk). HIV cannot be transmitted through body fluids such as saliva, sweat, tears or urine.</td>
<td>Blood, semen, pre-cum, vaginal fluids, breast milk</td>
</tr>
<tr>
<td>Aids or aids</td>
<td>AIDS is an acronym for Acquired Immune Deficiency Syndrome. Using lower case letters is incorrect for acronyms.</td>
<td>AIDS</td>
</tr>
<tr>
<td>Inappropriate language</td>
<td>Why?</td>
<td>Appropriate language</td>
</tr>
<tr>
<td>------------------------</td>
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</tr>
<tr>
<td>AIDS sufferers</td>
<td>Many people living with HIV are healthy and live positive lifestyles. They should not be portrayed as suffering.</td>
<td>People living with HIV or AIDS (PLHA)</td>
</tr>
<tr>
<td>AIDS victims</td>
<td>Victim implies powerlessness, people living with HIV are not victims.</td>
<td>People living with HIV or AIDS (PLHA)</td>
</tr>
<tr>
<td>AIDS carriers</td>
<td>No one carries AIDS. AIDS is the period when an individual’s immune system is damaged by HIV infection, leaving them vulnerable to opportunistic infections.</td>
<td>People living with HIV or AIDS (PLHA)</td>
</tr>
<tr>
<td>Full-blown AIDS</td>
<td>This term implies there is such a thing as ‘half-blown AIDS’. AIDS is simply AIDS. Referring to a term such as ‘full-blown AIDS’ is an unnecessary exaggeration.</td>
<td>AIDS</td>
</tr>
<tr>
<td>AIDS test</td>
<td>When one is tested, it is the HIV antibodies that are identified, not AIDS. One has an HIV test.</td>
<td>HIV test</td>
</tr>
<tr>
<td>HIV virus</td>
<td>HIV stands for human immunodeficiency virus. Therefore, it is incorrect to refer to it as HIV virus.</td>
<td>HIV</td>
</tr>
<tr>
<td>AIDS orphans</td>
<td>Children who have lost either one or both of their parents to AIDS-related illnesses are orphans. They may or may not be infected with HIV. The term AIDS orphans sets them apart from other orphans, yet the issues influencing their health and well-being are the same. By distinguishing children as AIDS orphans we further perpetuate stigmatisation of and discrimination towards these children.</td>
<td>Children affected by HIV/AIDS or children infected with HIV in the case of HIV-positive children.</td>
</tr>
<tr>
<td>Innocent/guilty</td>
<td>Using the adjective of ‘innocent’ (i.e. innocent children infected with HIV) implies that there are people who are guilty of infecting them or themselves. Using these adjectives promotes stigma around HIV/AIDS.</td>
<td>Avoid using descriptive adjectives</td>
</tr>
</tbody>
</table>
HIV/AIDS global epidemic overview

Global statistics

According to UNAIDS in 2004 there were 39.4 million people living with HIV across the world in 2004 (2.2 million of them were children under 15), 4.9 million people were newly infected and 3.1 million died of AIDS-related illnesses.

Africa

Sub-Saharan Africa has just over 10% of the world’s population, but is home to more than 60% of all people living with HIV – some 25.4 million. In 2004, an estimated 3.1 million people in the region became newly infected, while 2.3 million died of AIDS. Among young people aged 15-24 years, an estimated 6.9% of women and 2.2% of men were living with HIV at the end of 2004.

Adult HIV prevalence has been roughly stable in recent years. But stabilisation does not necessarily mean the epidemic is slowing. On the contrary, it can disguise the worst phases of an epidemic – when roughly equally large numbers of people are being newly infected with HIV and are dying of AIDS.

Southern Africa remains the worst affected sub-region in the world, with South Africa having the highest number of people living with HIV in the world. Life expectancy at birth has dropped below 40 years in nine African countries – Botswana, Central African Republic, Lesotho, Malawi, Mozambique, Rwanda, Swaziland, Zambia and Zimbabwe. All are severely affected by AIDS. In Zimbabwe, life expectancy at birth was 34 years in 2003, compared with 52 years in 1990.

Some countries in east Africa, such as Ethiopia, Kenya and Uganda, show signs of decline in HIV infection levels. The steepest drop has been in Uganda, where national prevalence fell from 13% in the early 1990s to 4.1% by the end of 2003. However, it is much too early to claim that these recent declines herald a definitive reversal in these countries’ epidemics and, furthermore, the need for treatment, care and support will continue to increase for years to come.

HIV/AIDS in South Africa

Prevalence

The South African epidemic was the last to develop in Africa and is one of the most severe in the world. The 2002 Nelson Mandela/HSRC Study of HIV/AIDS estimated that 11.4% of all South Africans are infected with HIV – it also found that while there was no gender difference in prevalence, female youth had far higher prevalence rates than male youth.

Antenatal HIV prevalence surveys have been conducted annually in South Africa since 1990. The findings of the 2004 survey indicate that HIV prevalence among pregnant women who attended public health antenatal clinics was 29.5%, compared to the 27.9% observed in 2003.

But this was a survey of pregnant women who attend antenatal clinics. Although this is not a representative sample of all South Africans, researchers can extrapolate this information and estimate how many people in South Africa have HIV/AIDS. In 2003, the researchers acknowledged four assumptions:

Assumption 1: The prevalence rate of HIV infection in all pregnant women in South Africa is the same as the prevalence rate in women attending public antenatal clinics.

Assumption 2: The prevalence rate of HIV infection in all women aged 1 to 9 years is the same as the prevalence rate in pregnant women.

Assumption 3: Estimate of males infected = 8% of infected females.

Assumption 4: The mother-to-child transmission rate = 30%.

Possibly the most contentious assumption is that the prevalence rate of pregnant women is the same as that of all women of child-bearing age. Pregnant women are by definition practising unsafe sex, placing them at a higher risk of HIV infection. Yet studies have also shown that HIV lowers fertility, perhaps balancing the equation.

Taking these assumptions into account the Department of Health estimated that these figures translated into 5.6 million HIV-positive South Africans, including 3.1 million women (15 to 49 years), 2.4 million men (15 and 49 years) and 96 228 babies.

The Eastern Cape, KwaZulu-Natal and Limpopo showed statistically significant increases in prevalence. The Western
Cape and Northern Cape showed increases that were not statistically significant. Gauteng, Mpumalanga, the Free State, and North West did not have consistent prevalence patterns over the three-year period.

Prevalence and age and gender

HIV infection was higher among women in their late twenties and early thirties and lower among teenagers. Nearly 0% of women aged between 2 and 29 years were HIV positive. Women in the early twenties and early thirties show lower rates at around 30% prevalence. Older women and teenagers showed prevalence rates below 20%. The survey estimated an HIV prevalence rate of 29.5%.

From March to August 2003 a national survey of HIV prevalence and sexual behaviour among 11 901–2 year olds was conducted. Multivariable models for HIV infection were restricted to sexually experienced youth. The survey showed that young women were significantly more likely to be infected with HIV than young men (15.5% versus 4.8%). Among females, HIV prevalence rose from 4% among 15 and 16-year-old females to 31% among women aged 21 years. Among males, HIV prevalence was relatively constant at 2–3% between ages 15 and 19 years and then steadily rose to 11–12% by age 23–24 years. Among 20–24 year olds, nearly one in four young women was infected with HIV, in comparison with 1 in 14 young men of the same age. Young women with older partners were also at increased risk of HIV infection. Among both men and women, increasing partner numbers and inconsistent condom use were significantly associated with HIV infection.

Impact of ART

Projections by the Centre for Actuarial Research, the Medical Research Council and the Actuarial Society of South Africa suggest that ART could, even at this late stage of the epidemic’s progression, reduce the number of AIDS deaths per year. Without ART some 495 000 deaths due to AIDS in 2010 would have been expected, but with ART this would be reduced to approximately 380 000 – a difference of about 100 000 deaths in a year. There was uncertainty about the coverage of the ART rollout and the number of deaths in 2010 could be anything between 290 000 and 450 000. With the default scenario of the interventions, life expectancy was projected to fall to just under 50 years, compared with the previous estimate of 43 years. The life expectancy in 2004 was estimated to be 48.5 years for males and 52.7 years for females and the infant mortality rate was estimated to be 56 per 1 000 live births. There were a total of 1.1 million orphans (maternal orphans under the age of 18 years) of which just over 250 000 were newly orphaned in 2004. On the assumptions in the model it was estimated that about 500 000 people were in need of treatment. By October 2004, 19 500 people were receiving ART in the public sector. The population growth rate has been affected by HIV/AIDS and although falling, it was not expected to become negative: it was estimated to be about 0.8% in 2004 and was projected to fall still further to around 0.4% in the years beyond 2011.

Orphans

In 2003, 12.3% of all children in sub-Saharan Africa were orphans. The highest percentages of children orphaned were in countries with high HIV prevalence levels or those that have recently been involved in armed conflict. The number of AIDS orphans in South Africa was expected to reach nearly 2 million by 2010. Approximately 3.2 million children were orphaned in sub-Saharan Africa in 1990. In 2003, 5.2 million children in the region became orphans. In South Africa 15% or more of all orphans were orphaned in 2003. The majority of new orphans in South Africa lost their parent or parents to AIDS. The burden of orphan care was already seen to be shifting in countries with the highest HIV prevalence levels. Orphans are increasingly more likely to be living in female-headed and grandparent-headed households. Female-headed households also take in more orphans than male-headed households. In South African households that have assumed responsibility for orphans, there were on average two double orphans in each female-headed household, while in male-headed households the average was around one. While grandparents and other older caregivers already have an important role in the care of orphans, their burden is notably increasing.

The increasing proportion of orphaned children also places...
a tremendous strain on the social fabric of communities and nations. Even cultures and communities with strong social cohesion and traditions of providing support to orphans and other vulnerable children can be overwhelmed when the rate of increase and the overall number of orphans reach disproportionately high levels. An especially important and distinctive characteristic of HIV/AIDS in regard to orphaning is that AIDS is more likely than other causes of death to create double orphans. In the case of HIV/AIDS, there is a higher probability that one parent is or will become infected if the other parent is infected, and also that both will eventually die. This means that countries with high levels of HIV/AIDS will also have a disproportionate number of double orphans as the epidemic advances. Surveys consistently show that double orphans are more disadvantaged than single orphans. AIDS is changing the pattern of orphaning in sub-Saharan Africa, where maternal orphans now outnumber paternal orphans in five of the most affected countries. In the absence of HIV/AIDS, children were more likely to become orphans because of a father’s death. In the countries of sub-Saharan Africa today, however, women have higher rates of HIV/AIDS than men, and there are now more maternal orphans due to AIDS than paternal orphans due to AIDS. In the most affected countries in southern Africa, 60% of orphans have lost their mother.1

Risk factors

While HIV occurs in all social groups in South African society, certain people are more susceptible to HIV. This is because of risky behaviour patterns or because social circumstances make them less able to protect themselves.

High-risk situations include:

- multiple sexual relationships
- commercial sex work
- separation of people from their families
- living in single-sex quarters
- other sexually transmitted infections (STIs), and
- poverty.

Other factors that might contribute to the South African epidemic are:

- the disruption of family and communal life resulting from apartheid and migrant labour
- a good transport infrastructure
- the low status of women in society and relationships
- social norms which accept high numbers of sexual partners, and
- extensive resistance to condom use.

What is HIV?

H = human
I = immuno-deficiency
V = virus

HIV is the virus that causes AIDS.

- A person’s immune system is the body’s defence system, which protects it from diseases.
- This virus attacks the immune system and weakens it.
- HIV infection makes the immune system deficient and the infected person becomes sick.
- HIV infection is not a death sentence. A person can live a positive and productive life with HIV for a long time.
- If someone is infected with HIV s/he is said to be HIV positive.

What is AIDS?

A = acquired (get it from someone)
I = immune (body’s defence system)
D = deficiency (weakness, failure or inadequacy of the immune system)
S = syndrome (collection of various diseases and symptoms)

- AIDS is the end stage of HIV infection.
- At this stage various diseases attack the weakened body.
- These are called opportunistic infections.

Sexually transmitted infections

STI stands for sexually transmitted infections, i.e. diseases or infections that are passed on through sexual activity. In the constant focus on HIV/AIDS, STIs are frequently overlooked. This is a serious omission because other STIs are also dangerous, and sometimes fatal. The presence of an STI indicates unprotected sex, behaviour that puts people at risk for HIV infection. There is also an increased chance of HIV transmission when another STI is present. STIs serve as avenues for HIV to enter the bloodstream.

STIs can have serious consequences:
- some STIs can cause death, e.g. HIV/AIDS, syphilis
- some STIs can cause infertility, e.g. chlamydia, gonorrhea
- some can be passed from the mother to the baby, e.g. HIV/AIDS, syphilis, gonorrhea
- some cannot be cured, e.g. HIV/AIDS, genital herpes.

CD4 counts and viral loads

In order to understand the progression of HIV and treatment there are certain terms one must become familiar with, namely CD4 cell count and viral load.

CD4 cell count

HIV largely exerts its effect on the immune system by destroying CD4 cells (i.e. T-cells or T-helper cells), critical cells to help the body fight infections. The normal CD4 cell count ranges from 600 to 2 000 cells/mm\(^3\). Generally a person is said to have AIDS when the CD4 count drops to 200 and below. The CD4 cell count is one of the most useful markers of the state of the immunity in a person with HIV/AIDS.

Viral load

The viral load is a measurement of how much HIV is in the body. The higher the viral load, the more rapidly a person’s immune system will be damaged by CD4 cell destruction. Also, a higher viral load creates a greater chance that mutant HIV will arise, which is resistant to medication.

Modes of transmission

HIV is found in all fluids in the body of an infected person. Body fluids that contain sufficient quantities of the virus to facilitate infection are:
- semen
- vaginal secretions/fluid
- blood
- breast milk.

There are other body fluids that do not contain sufficient quantities of the virus to be infectious. These are:
- saliva
- sweat
- tears
- urine.

HIV is spread most commonly by unprotected penetrative sexual contact with an infected partner. The virus can enter the body through the lining of the vagina, vulva, penis and rectum during sex.

HIV is also spread through contact with infected blood. In this case drug users frequently spread HIV by sharing needles or syringes contaminated by the blood of someone infected with the virus. Transmission from patient to health care worker or vice-versa via accidental needle-stick injuries or other medical instruments is possible, but rare.

Women can transmit HIV to their unborn babies during pregnancy (across the placenta), at birth and through breastfeeding (mother-to-child transmission).

For infection with HIV to occur, two things must happen:
- the virus must find a way to enter the bloodstream, and
- the virus must ‘take hold’.

This is more likely to happen if there is sufficient virus in the fluid and one is exposed to the virus for a longer time. A useful way of thinking about this is to use the word SAD:
- \( S \) = sufficient quantities of the virus (i.e. semen, vaginal fluid, blood or breast milk)
- \( A \) = access to the bloodstream
- \( D \) = duration of exposure must be long enough (the risk of infection increases, the longer a person is exposed to the virus).
A few weeks after HIV infection, a person may have flu-like symptoms. This is sometimes called sero-conversion illness. After that, an average of 5 to 7 years will pass without another sign of infection, although that delay can range from a few months to 10 years. However, even when a person does not have symptoms, the virus is still multiplying in his/her body, and he/she can pass it to other people. Mild symptoms may occur when the immune system first starts to weaken (many of these can be effectively treated or prevented) but the symptoms become more severe as the AIDS stage of HIV infection is reached.

Rapid progressors will get to the AIDS stage quickly (within 2 to 5 years), slow progressors will take longer (within 7 to 10 years) and non-progressors may never get AIDS symptoms at all.

**Symptoms**

Some symptoms of primary infection (sero-conversion illness) are:
- fever
- tiredness
- rash
- sore throat
- muscle and joint pain
- swollen lymph glands.

Some symptoms of the minor symptomatic phase are:
- chronic swelling of the lymph glands
- herpes zoster (shingles)
- occasional fevers
- skin rashes
- fungal nail infections
- recurring oral ulcerations
- recurring upper respiratory tract infections
- weight loss.

Some symptoms of the symptomatic phase are:
- recurrent or persistent candida albicans (thrush) in the mouth and vagina (in women)
- hairy leukoplakia (white plaques) on the tongue
- herpes zoster and herpes simplex (cold sores)
- acne-like bacterial skin infections
- persistent and unexplained fevers and night sweats
- skin rashes
- generalised swollen lymph glands or shrinking of previously enlarged lymph nodes
- persistent diarrhoea
- weight loss of more than 10% of body weight
- reactivation of TB.

Some symptoms of AIDS are:
- skin rashes and skin conditions
- respiratory infections
- oral and genital thrush
- ongoing diarrhoea
- nausea and vomiting
- wasting of the body and tissue loss
- peripheral neuropathy (pains and tingling in hands and feet)
- headaches, fits and other neurological conditions
- tiredness, fatigue and weakness
- memory and concentration loss
- mental deterioration and confusion
- any of a number of opportunistic infections such as: mycobacterium TB, cytomegalovirus (CMV), pneumocystis carinii pneumonia (PCP), toxoplasmosis, cryptococcal meningitis, Kaposi’s sarcoma (KS) and lymphoma.
Diagnosing HIV

HIV is diagnosed by having an HIV test. It is a legal and ethical requirement that all HIV testing be accompanied by informed consent and pre-test and post-test counselling. The following blood tests can be used to diagnose HIV:

- ELISA (enzyme-linked immunosorbent assay): this looks for antibodies1 against HIV
- Western blot: can be used to confirm a positive ELISA result
- rapid test: an antibody test which can be performed outside a laboratory
- P2 antigen test: measures the proteins of the virus
- PCR: detects viral genetic material
- saliva test: is a quick and easy test for HIV
- lastly, the HIV RNA viral load quantification or HIV RNA assay is a relatively new test (RNA is the form in which HIV particles carry their genetic material). This test measures the number of viral particles or ‘copies’ per ml of blood. A rising viral load indicates very active HIV disease.

The ELISA and Western blot tests are the most commonly used tests in the field. The new ‘rapid test’ is based on the ELISA test. The P2 antigen and PCR tests are not widely used because they are more expensive than the other two. The saliva test is a non-blood test, which can also be used to see if a patient is HIV positive. It tests for HIV antibodies and works on the same principle as the rapid test.

The rapid tests are very useful in under-resourced areas of the country where people are far removed from diagnostic laboratories and where clients often cannot afford to go back for their results. A positive rapid test should always be confirmed with a laboratory-based ELISA antibody test. The government has developed a national voluntary counselling and testing (VCT) campaign in which the rapid test is used to test people for HIV infection.

The window period

The window period is the period between the onset of HIV infection and the appearance of detectable antibodies to the virus. In the case of the most sensitive HIV antibody tests currently recommended, the window period is about 3 to 4 weeks. This period can sometimes be longer (approximately 6 weeks) if one uses less sensitive tests. In some cases, the window period can be up to 12 weeks, or (in rare cases) between 6 and 12 months before antibody tests can give positive results.

Any blood tests (such as the ELISA, rapid test and Western blot) conducted during the window period may give false negative results. This means that although the virus is present in the person’s blood there are, as yet, no (detectable) antibodies in the blood. In such cases the tests erroneously show that the person is not infected. In this period the person is already infectious and may unknowingly infect others.

Prevention

The pursuit of an AIDS vaccine remains a critical international goal. Increasingly funds are being made available for this purpose. Clinical trials of vaccine candidates are presently under way. Until there is an effective vaccine, social mobilisation toward healthier and safer sexual behaviour should be increased significantly and sustained. Data shows continuing high rates of HIV infection in the sexually active population. This indicates continued high-risk behaviour, which has been confirmed by various behavioural surveys.

The greatest barriers to achieving HIV prevention are fear, denial and ignorance. HIV prevention efforts have been plagued above all by silence brought on by the denial and stigmatisation that is associated with the disease. In one study of home-based care schemes in southern Africa, fewer than one in ten people who were caring for an HIV-infected patient at home acknowledged that their relative was suffering from HIV. Patients themselves were only slightly more likely to acknowledge their status.

There is a danger that the large-scale provision of anti-retroviral drugs could undermine prevention efforts. There is already a dangerous pessimism that prevention efforts do not work in South Africa, despite convincing scientific evidence from other highly affected, poorly resourced countries of plummeting rates of infection as a result of sustained and well-targeted prevention efforts. This pessimism could be compounded if

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14 Antibodies are special protein complexes that are produced by the immune system. They attack and neutralise specific disease-causing organisms. The antibodies, which the body creates in response to HIV, are unfortunately powerless to protect the body against the long-term destructive effects of the virus on the human body.
at-risk populations perceive anti-retroviral drugs as a curative solution to HIV infection. Scarce resources for HIV prevention efforts may also be diverted to the provision of these drugs.

Achieving sexual behaviour change is a complex task, requiring integrated inter-sectoral approaches implemented at all levels of society and sustained over a considerable number of years. Prevention initiatives need to succeed in creating a social consciousness and environment that will facilitate appropriate personal action.

Since there is no vaccine for HIV yet, the only way to prevent infection is to avoid behaviour that puts a person at risk of infection, such as sharing needles and having unprotected sex.

Mother-to-child-transmission (MTCT)

There have been great advances in the prevention of mother-to-child transmission of HIV. Pregnant women can be given AZT or Nevirapine (or combinations of anti-HIV drugs) during pregnancy, labour and delivery to reduce their viral load and thus lessen the risk of transmission to the baby. In the case of AZT, the baby should also take one of these drugs for the first six weeks of life to further lessen the risk. In the case of Nevirapine, only a single dose is needed at birth. Other strategies include practising safer sex during pregnancy, choosing to have a Caesarean section birth, and vaginal washing during delivery.

Post-exposure prophylaxis

There have been excellent results in preventing HIV transmission in health workers who have had needle-stick injuries, by giving them anti-HIV drugs within an hour of the injury and then for a month afterwards (which is known as post-exposure prophylaxis). More or less the same protocol is used with rape survivors. Prophylactic treatment for rape survivors should start within 72 hours after the assault.

Microbicides

The word ‘microbicides’ refers to a range of different products that share one common characteristic: the ability to prevent the sexual transmission of HIV and other sexually transmitted infections (STIs) when applied topically. A microbicide could be produced in many forms, including gels, creams, suppositories, films, or as a sponge or ring that releases the active ingredient over time.

Scientists are currently testing many substances to see whether they help protect against HIV and/or other STIs, but no safe and effective microbicide is currently available to the public. However, scientists are seriously pursuing almost 60 product leads, including at least 11 that have proven safe and effective in animals and are now being tested in people. If one of these leads proves to be successful and investment is sufficient, a microbicide could be available in 5 to 7 years.

Microbicides would fill an important gap in our ability to prevent HIV and STIs. Current prevention options – condoms, mutual monogamy and STI treatment – are not feasible for millions of people around the world, especially women. Many women do not have the social or economic power necessary to insist on condom use and fidelity, or to abandon partnerships that put them at risk. Because microbicides would not require a partner’s co-operation, they would put the power to protect into women’s hands.

Vaccines

An HIV/AIDS vaccine teaches the body to recognise the human immuno-deficiency virus (HIV) that causes AIDS, and will cause an immune response that should kill or disable the virus if it enters the body. Currently, there are no HIV vaccines that are effective in preventing HIV infection. However, there are a number of vaccines that need to be tested in clinical trials. Testing a vaccine to ensure that it is both safe and effective takes a long time.

There are currently a number of potential vaccines being developed in South Africa. Coordination of the research, development and testing of all these vaccines is the responsibility of the South African AIDS Vaccine Initiative (SAAVI). All vaccine trials have to be approved by the Medicines Control Council (MCC) and local ethical review boards. An important part of the vaccine initiative is to mobilise communities to become involved in the process of clinical trials, under the South African HIV Vaccine Action Campaign (SA HIVAC).

On 19 June 2003, SAAVI announced that the South African Medicines Control Council (MCC) had approved the first human clinical trial for a phase I HIV vaccine trial in South Africa. The trial involved a small number of volunteers in the USA and South Africa (48 in the USA and 48 in South Africa). On 25 August 2003, the MCC approved a second preventative vaccine for clinical trials. South Africa has become a key centre in the global effort to discover a vaccine. The phase I trials commenced on 3 November 2003.
Safer sex

Safer sex means making sure that a person does not get anyone else’s blood, semen, vaginal fluids, or breast milk into his or her body, as well as protecting partners while having sex. Safer sex reduces the risk of infection, but does not eliminate it.

Safer sex interventions in a country where there is a predominantly patriarchal society are difficult. The low status of women means it is not easy for them to protect themselves. Safer sex should be a mutual agreement by both parties to make sex more enjoyable and interesting. Safer sex also entails deciding when and how sex should take place.

Sexual practices can be seen on a continuum from those which carry a high risk of infection to those that carry little or no risk of infection.

High-risk activities include:
- vaginal or anal penetration without a condom
- sharing uncovered sex toys
- sharing needles, razor blades or any sharp tool that can pierce or cut the skin.

Activities with some risk include:
- oral sex performed on a man without a condom
- oral sex performed on a woman without a barrier
- vaginal or anal penetrative sex with a condom. The risk depends on how the condom is used, its age and type of lubricant used with it
- monogamy. The risk depends on the behaviour of the partners.

Low-risk activities include:
- oral sex on a man with a condom
- oral sex performed on a woman with a barrier
- deep (French) kissing.

No-risk activities include:
- abstinence
- erotic massage
- hugging and body rubbing
- masturbation and mutual masturbation
- sexual fantasy.

Abstinence and monogamy

The simplest answer to avoid HIV infection is abstinence, meaning no sex at all. Another way is to reduce the risk is to limit sex to a monogamous relationship with an uninfected partner. Having multiple partners without condoms is dangerous. While abstinence and monogamy do work, for many complicated psychological and social reasons they are not easy to achieve and prevention messages should include, in a non-judging way, messages about condom use.

Condoms

Before the invention of the contraceptive pill, the condom was one of the most popular contraceptives. The worldwide HIV/AIDS epidemic prompted a renewed interest in the condom, because it is one of the cheapest and most successful ways to curb the spread of HIV. By using a condom correctly, the chances of contracting HIV is decreased 10 000 fold.

The best condoms to use for vaginal and anal intercourse are lubricated latex condoms. (Because some people show allergic reactions to latex there are non-latex variants available; but these non-latex condoms cannot prevent the transmission of HIV.) Some people question the effectiveness of condoms; this is usually because of an inability to use them properly. Laboratory studies generally have found that viruses do not pass through intact latex condoms, even when the devices are stretched and stressed. Thus, if condoms are used consistently and correctly, they prevent HIV transmission.

Using lubricants will make sex go smoother and give added protection. It is important to always use water-based lubricant, such as KY-jelly or plain white yoghurt. Oil-based creams such as Vaseline, Dawn Cream, aqueous cream, hand and body lotions cannot be used, as oil breaks down latex. Even treatments for yeast infections contain oil and will break down latex.

Female condoms

The female condom or femidom is made of durable polyurethane. It allows a woman to assume control over HIV transmission. The female condom is slipped inside the vagina and provides a lubricated barrier that is stronger than latex. It can be inserted up to 8 hours prior to intercourse, which means that it does not break the spontaneity of sexual play as latex condoms can do.
Dental dams

Dental dams are rectangular squares of latex that are used during oral sex, both oral-vaginal and oral-anal. During sex dental dams are stretched over the partner’s genitals to prevent the person’s tongue from touching the partner’s bodily secretions. They are an effective way of disease prevention, but difficult to hold in place. Some water-based lubricant placed on the genital side of the dam will help to keep it in place.

**Treatment**

Once a person has been diagnosed as HIV positive, it is important to do a clinical assessment of the person’s health. The person who is HIV positive should have regular check-ups to monitor any changes in their health (at least every 6 months if the person is healthy, but more frequently if the person has symptoms). Regular check-ups can help health care professionals to identify and treat physical and psychological problems at an early stage and to promote the general health of the HIV-positive person.

Even when people do not have access to expensive treatment, changes in behaviour will help them to lead a better life, such as getting plenty of rest, exercise, a good balanced diet, good stress management, a positive mental attitude, social support and alternative treatment options (e.g. traditional healers, aromatherapy, etc.).

When the AIDS pandemic began, no drugs were available to combat the underlying immune deficiency and few treatments existed for opportunistic infections. However, over the past 12 years, anti-retroviral drugs (ARVs) have been developed to fight both HIV infection and its associated infections and cancers. ARVs are still relatively expensive. The ultimate purpose of ARVs is to reduce the viral load as much as possible – preferably to undetectable levels – for as long as possible. Because this means that less damage will be inflicted on the immune system, the person will experience an improvement in his/her immune functioning and the onset of AIDS will be delayed. A combination of three different ARVs has been shown to produce the best effects and to reduce the chances of viral resistance.

**How the drugs work**

ARVs act by blocking the action of the enzymes that are important for HIV functioning and making copies of itself. The different drugs target the enzymes at different stages of the HIV replication cycle.

**What do we do when traditional beliefs clash with HIV/AIDS information?**

It is important within the context of HIV/AIDS to challenge traditional beliefs and cultural practices which have harmful consequences. It is important that we realign that culture is always changing and the way in which it changes can be influenced. Traditional practices that put both men and women in danger of being infected with HIV/AIDS should be challenged irrespective of whether these practices are said to be ‘culture’, e.g. prevailing norms of masculinity that expect men to be more knowledgeable and experienced about sex, put men, particularly young men, at risk of infection because such norms prevent them from seeking information or admitting their lack of knowledge about sex or protection, and coerce them into experimenting with sex in unsafe ways, and at a young age, to prove their manhood. No one group should manipulate and claim a monopoly of culture through oppression of others, particularly the oppression that is based on gender.

While the South African government has undertaken to make ARVs available at certain public hospitals throughout the country, the implementation of this programme has been slow and many people still do not have access to the medications.

There are currently three main categories of anti-retroviral drugs:

- nucleoside reverse transcriptase inhibitors (NRTIs) or nukes
- non-nucleoside reverse transcriptase inhibitors (NNRTIs) or non-nukes
- protease inhibitors (PIs).

For the best viral suppression, triple therapy is recommended. Combination treatment with 2 NRTIs and one PI is recommended for optimum effect. Most patients on this triple-therapy treatment programme will reach the target of undetectable HIV-RNA levels in the blood. The NRTI-PI triple therapy regime is, however, very expensive and the alternative recommendation is a combination of 2 NRTIs plus an NNRTI.

Mono-therapy (treatment with only one agent, such as AZT) is no longer recommended for HIV therapy because it produces a temporary reduction in viral load, and the patient develops resistance to the drug within weeks or months. Mono-therapy with AZT is only used in some cases as a short-term limited course treatment of HIV infection in pregnant mothers, so as to prevent transmission to the baby.

Resistance refers to the ability of HIV to change its chemical (or 'genetic') structure so that it resists the effects of drugs. The virus will develop resistance much faster when mono-therapy is used. Resistance is a complicated problem. If a person develops resistance to a drug, it does not always mean that the person should stop taking that drug and will never be able to take it again, because not all the viruses in the body might be resistant to that drug. It will still be able to reduce the viral load to a certain extent.
Side-effects

Dealing with drug side-effects can be a challenge. Every drug used to treat infections may have side-effects. ARVs have their own set of possible side-effects. These may vary from one person to the next. Some people have no side-effects, while some experience mild and manageable side-effects. A small number of people have quite severe side-effects. On starting ARVs, many people have an adjustment period when side-effects occur. This period usually lasts about one to four weeks, as the body adapts to the new drug. The person may experience headaches, nausea, muscle pain in the arms and occasional dizziness. These kinds of side-effect typically lessen or disappear as the body adjusts.

The key to coping with side-effects is knowing what to watch out for and having a plan in place to respond if problems occur. It is possible to prevent or reduce the seriousness of some side-effects by taking certain preventive therapies a few days before or at the same time as starting a new regimen of drugs.

Adherence

Adherence to ARVs is critical for their success. It is known that while adherence is possible, some people struggle to maintain it for life. For more information on adherence, including material on counselling and training of counsellors on adherence, you can refer to the Adherence Resource Pack. A copy is available from the CSA at www.csa.za.org or through HIVSA at www.hivsa.com.

Preventing infections

As a PLHA’s immune system gets damaged, a point is reached when he/she is vulnerable to serious infections called opportunistic infections. The risk of developing these is greater when the CD4 count drops below 200. At this point a doctor may recommend that a person take medication to prevent certain infections. This is called primary prophylaxis – preventing an illness before it occurs.

If an infection develops and the person recovers, he/she may need drugs to prevent it from recurring. This is called secondary prophylaxis or maintenance therapy. Better drugs for opportunistic infections have increased the life expectancy of people with HIV. For some infections there are very effective drugs, for example for PCP, a form of pneumonia. However not all infections can be easily prevented. Deciding whether or not to take a prophylaxis means weighing up the benefits of preventing the infection against the inconvenience of taking medication and the risk of side-effects. Some drugs have to be taken at certain times of the day or with certain foods and this means changes in the daily routine.

Treating infections

Some people do not like the idea of prophylaxis, or they go to their doctors when they are already ill, or they may not have known they are HIV positive. Thus they may need treatment for a current opportunistic infection. When treated early enough, most infections can be eradicated successfully. However opportunistic infections are serious and are the main cause of death amongst PLHA. People who develop opportunistic infections nearly always lose weight, which may be difficult to regain, and this increases the risk of further illness.

How can a person access ARVs?

If Jabu would like to get anti-retroviral (ARV) drugs, he will need to present himself at one of the government’s ‘service points’, where he will get voluntary HIV counselling and testing. If he tests positive, Jabu will then be advised to have a CD4 test, especially if he has opportunistic infections. The CD4 cells coordinate the body’s immune response, so the test measures the strength of his immune system. His viral load (levels of virus in the body) will also be measured. Most provinces rely on national laboratories to process these results.

If Jabu’s CD4 count is less than 200 copies per millilitre of blood, he will be advised to go onto ARV treatment. If his CD4 count is higher than 200 but he has an AIDS-defining illnesses (according to the World Health Organisation definition) he will still be eligible for the drugs.

These drugs will have to be ordered from the provincial pharmaceutical stores and will take about three weeks to be delivered.

During that three-week wait, Jabu needs to attend three treatment literacy training sessions. These will explain how the drugs work and the importance of adhering strictly to the treatment.

Once he is on the ARVs, he will need to return for monthly check-ups and his CD4 count and viral load will be tested every six months. If his viral load does not fall to undetectable levels within six months, this might mean that he is not responding to the drugs and his regimen will be changed.

Adapted from Health-e News Service (www.health-e.org.za).

Quality

For transmission to take place, the quality of the virus must be strong. HIV cannot survive outside the human body – it starts to die as soon as it is exposed to the air. If it is exposed to heat (for example if someone bleeds into a cooking pot) it will die. HIV does not live on the surface of the skin – it lives inside the body. The only place the virus can survive outside the body is in a vacuum (like a syringe) where it is not exposed to air.

Quantity

For transmission to take place, there must be enough quantity of the virus to pose a risk. HIV is found in large quantities in blood, semen and vaginal fluids and breast milk. It is not found in sweat or tears. It is found in tiny amounts in saliva, vomit, faeces and urine but not enough for there to be any risk of transmission, unless blood is present.

Route of transmission

For HIV transmission to take place, the virus must get inside your bloodstream. Our body is a closed system. HIV cannot pass through unbroken skin or even broken skin very easily. If you cut yourself, the blood flows outwards, away from the bloodstream. If you touch someone else’s cut, blood will not swim into your bloodstream!

Common sense and everyday hygiene mean that many concerns that people worry about would not really happen in everyday life. For example you wouldn’t share a toothbrush if it was covered in blood; you would wash if you cut yourself; you would wear gloves or cover your hands if you were cleaning up someone’s diarrhoea.

Using “QQR” you can see why HIV cannot be transmitted by:

- kissing
- hugging
- mosquitoes
- sharing cups and plates
- shaking hands
- giving blood
- sharing toilets
- using the same washing water
- going to school together.
### Frequently asked questions (FAQs) about HIV/AIDS

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<th>Answer</th>
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<tr>
<td>Can mosquitoes transmit HIV from human to human?</td>
<td>No. The HIV virus cannot live outside the human body. Mosquitoes do not inject blood into humans, they suck blood. (There is no “QQR”.)</td>
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<tr>
<td>Can HIV be transmitted through razor blades or sharp instruments?</td>
<td>There is a slight risk – where a razor is being used quickly to make incisions or cuts on many people one after the other without washing it. It is better and more hygienic anyway to sterilise sharp instruments by boiling them, or use new razors every time. In terms of sharing razors to shave or cut hair – if a razor is covered in blood you would probably not use it anyway – or you would wash it thoroughly.</td>
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<tr>
<td>Can I get HIV by touching someone who has open cuts and sores?</td>
<td>No. Unless someone is covered in blood and you are injured badly yourself with open wounds, then there is no risk. Your skin protects you. If you are bleeding, your blood flows outwards, it does not suck things into your bloodstream! Good hygiene would mean that if you are caring for someone (with HIV or not) and they are bleeding, you would use gloves or cover your hands, and wash well before and afterwards.</td>
</tr>
<tr>
<td>What about cleaning up diarrhoea of an HIV patient?</td>
<td>There is no risk. Diarrhoea does not contain the HIV virus, unless it has blood in it. And it would still have to get inside your bloodstream. Use gloves or cover your hands for hygiene reasons anyway.</td>
</tr>
<tr>
<td>How long can you live if you get HIV/AIDS?</td>
<td>This depends on many things. If you are healthy and can eat well and have lots of love and support, you can live for many years. If you can access antiretroviral drugs and take them consistently, you can live many years. Remember that HIV and AIDS are different things. With HIV you have the virus but you are healthy, With AIDS, it means your immune system is low and you may have a number of infections (or opportunistic infections). It is important to treat these infections. Just remember finding out you are HIV positive is NOT a death sentence.</td>
</tr>
<tr>
<td>Is it true that condoms are not really safe?</td>
<td>If used properly, condoms offer 98% protection against HIV (and pregnancy). The virus cannot pass through a condom. Make sure your condoms are not out of date, and store them in a cool place. Don’t use Vaseline or oil on them as this can make them break. Never use more than one condom at a time! Some churches teach that condoms are not safe but this is not true.</td>
</tr>
<tr>
<td>Is there any cure for AIDS?</td>
<td>There is no cure but there are more and more treatments available which slow down the impact of HIV. These are called anti-retroviral drugs or ARVs. They are widely available in Western countries, and people there no longer think that HIV means you will die. ARVs are becoming more available, cheaper and easier to access in Africa.</td>
</tr>
</tbody>
</table>
1. You have the right to equality and freedom from discrimination

The law must treat, protect and benefit everyone equally. No person shall be discriminated against because of his or her race, gender, sex, pregnancy, marital status, ethnic or social origin, colour, sexual orientation, age, disability, religion, conscience, belief, culture, language or birth. Measures designed to protect or advance people in order to achieve equality (such as affirmative action programmes) may be necessary to guarantee this right.

2. Your human dignity will be respected and protected

You have the right to be treated with respect and dignity at all times. No one can insult you because of your race, colour or appearance.

3. You have the right to life

Nobody has the right to deprive you of your life. In South Africa the death penalty has been ruled unacceptable in terms of this right. In some countries this is given a wide meaning and can include the right to basic life necessities such as food, shelter, work and health care.

4. You have the right to freedom of the person and control over your body

You have the right to be free. Your freedom cannot be taken away from you unless the law allows this, for example, if you are arrested on suspicion or sentenced for committing a crime. You cannot be detained without trial, tortured or treated inhumanely. You have the right to make your own decisions concerning reproduction.

5. Servitude and forced labour cannot be inflicted on you

Slavery is forbidden by the Bill of Rights. You cannot be forced to work for anyone against your will or to work without pay.

6. You have the right to privacy

Your home and person are private. No one can search your home or person or interfere with your post and telephone, unless a crime is being investigated and the law governing searches is respected.

7. You have the right to freedom of religion, belief and opinion

You have the right to practise whatever religion you wish without interference. You can belong to any political party of your choice and hold any opinion you wish. You cannot be forced to do something against your conscience or beliefs. This right also provides that traditional law may be recognised in certain areas, provided that it does not conflict with any other fundamental rights.

8. You have the right to freedom of expression

You have the right to say what you like, whether this means speaking out against the government or putting forward a view that is not popular. This also includes freedom for the media, artists and researchers. However, this right does not permit war propaganda or the promotion of hatred or imminent violence.

9. You have the right to freedom of assembly, demonstration and petition

All people are free to attend meetings, demonstrate and present petitions, as long as they do so peacefully and without carrying weapons. A peaceful demonstration cannot be banned.

10. You have the right to freedom of association

You have the right to join any organisation of your choice. Any group of people with a common interest have the right to meet together and constitute themselves as an association or organisation in accordance with the law.

11. You have political rights

You have the right to make your own political choices. You have the right to join the political party of your choice and to participate in its activities, or to form your own party, recruit members and campaign. All citizens have the right to regular, free and fair elections. All adult South Africans have the right to vote in secret and to stand for election.

12. South Africans have citizen’s rights

South African citizens cannot have their citizenship taken away from them without proper reason. Citizens have the right to enter, remain in and leave the country. You have the right to a passport.
13. You have the right to freedom of movement and residence

Everyone has the right to travel freely anywhere in South Africa and to leave the country. All South African citizens can live in any province, town and residential area they choose. However, the authorities do have the right to regulate the informal residential occupation of land.

14. You have the right to freedom of trade, occupation and profession

You have the right to try to make a living anywhere in South Africa and to practise the trade or profession of your choice, although the government can regulate how you practise. (For example, it may require doctors to have certain qualifications.)

15. You have the right to fair labour practices

You have the right to fair labour practices in the workplace. You cannot be unfairly dismissed, paid below the minimum wage in your industry or deprived of leave or sick pay. Workers have the right to join and participate in the activities of a trade union. They also have the right to collective bargaining and to strike. Employers have the right to form employers’ organisations.

16. You have the right to a clean environment

You have the right to an environment that is not harmful to your health or well-being. The state must ensure that pollution is prevented and that rubbish is properly disposed. Cleanups and conservation must be promoted.

17. You have property rights

You have the right to hold property that belongs to you. The state may only take away your property if it is in the public interest to do so, for example for the building of a road or school. Land may also be redistributed to redress injustices arising from past racial discrimination. When property is taken away by the state, the owners must receive just compensation.

18. You have the right to housing

All people have the right to adequate housing. The state must take all reasonable steps to guarantee this right. This right also means that no one can evict people from their homes or demolish dwellings without full respect for the law.

19. You have the right to health care, food, water and social security

All people have the right to sufficient food and water. People who are unable to support themselves have the right to social security. All people have the right to health care, including reproductive health care. Nobody can be refused emergency medical treatment.

20. Children are specially protected by the Bill of Rights

Children under the age of 18 have the right to proper care and security, basic nutrition, shelter, basic health care and social services. They cannot be exploited in the workplace or be allowed to do dangerous or unhealthy work. They have the right to be protected from neglect, abuse and degradation.

21. You have the right to education

Everyone has the right to a basic education. This right includes basic literacy for adults. You have the right to be educated in the official language of your choice, where this can reasonably be done. People also have the right to establish private schools, provided that they do not discriminate on the basis of race and maintain acceptable standards.

22. You have language and cultural rights

You have the right to use the language of your choice. You can participate freely in cultural life by practising whatever customs and traditions you like, provided that you do not violate others’ rights.

23. Cultural, religious and linguistic communities have rights

All people and communities are entitled to enjoy their culture, practise their religion and use their language. They also can organise associations based on their culture, religion or language, provided this does not infringe upon other fundamental rights. Cultural Councils have the right to be established and recognised.
24. You have the right to access to information

You have the right to all information held by any state department that you may need to exercise and protect your rights. However, certain information may be withheld on the grounds of state security. Different countries give their countries different amounts of access to government information. The exact meaning of this right may be specified further by Parliament if it passes an Open Democracy bill.

25. You have the right to administrative justice

You have the right to be treated fairly and lawfully by any government official. You are also entitled to be given reasons for administrative decisions. If you believe that an administrative decision was wrong or unreasonable, it can be reviewed by a court of law.

26. You have the right to access to the courts

It is your right to have disputes settled by an independent and impartial court. The courts must serve all South Africans equally and fairly. Courts hear both criminal and civil cases.

27. Detained, arrested and accused persons have rights

No one can be arrested or detained without good reason and proper legal procedures must be followed. Detainees have the right to be informed in a language they understand of the reason for their arrest. Prisoners have the right to be kept in humane conditions and to have access to a lawyer, doctor, religious counsellor and spouse or partner. People arrested must be told of their right to remain silent. Anyone charged with a crime has the right to a fair trial by an impartial court, without ‘unreasonable delay’. Anyone accused of a crime is considered innocent until they are proven guilty in a court.

NOTE: The Bill of Rights provides that rights can be limited under certain circumstances

It is important to note that rights are not absolute. The Bill of Rights provides that they can be limited as long as the limitation is “reasonable and justifiable in an open and democratic society”, taking into account several factors, including the nature of the right, the nature and extent of the limitation, the purpose of the limitation and whether there are less restrictive means that could accomplish the same purpose.
Summary of Preamble

The General Assembly recognises that the inherent dignity and the equal and inalienable rights of all members of the human family is the foundation of freedom, justice and peace in the world, human rights should be protected by the rule of law, friendly relations between nations must be fostered, the peoples of the UN have affirmed their faith in human rights, the dignity and the worth of the human person, the equal rights of men and women and are determined to promote social progress, better standards of life and larger freedom and have promised to promote human rights and a common understanding of these rights.

A summary of the Universal Declaration of Human Rights

1. Everyone is free and we should all be treated in the same way.
2. Everyone is equal despite differences in skin colour, sex, religion, and language, for example.
3. Everyone has the right to life and to live in freedom and safety.
4. No one has the right to treat you as a slave nor should you make anyone your slave.
5. No one has the right to hurt you or to torture you.
6. Everyone has the right to be treated equally by the law.
7. The law is the same for everyone, it should be applied in the same way to all.
8. Everyone has the right to ask for legal help when his or her rights are not respected.
9. No one has the right to imprison you unjustly or expel you from your own country.
10. Everyone has the right to a fair and public trial.
11. Everyone should be considered innocent until guilt is proved.
12. Everyone has the right to ask for help if someone tries to harm you, but no one can enter your home, open your letter or bother you or your family without a good reason.
13. Everyone has the right to travel as they wish.
14. Everyone has the right to go to another country and ask for protection if they are being persecuted or are in danger of being persecuted.
15. Everyone has the right to belong to a country. No one has the right to prevent you from belonging to another country if you wish to.
16. Everyone has the right to marry and have a family.
17. Everyone has the right to own property and possessions.
18. Everyone has the right to practise and observe all aspects of their own religion and change their religion if they want to.
19. Everyone has the right to say what he or she think and to give and receive information.
20. Everyone has the right to take part in meetings and to join associations in a peaceful way.
21. Everyone has the right to help choose and take part in the government of his or her country.
22. Everyone has the right to social security and to opportunities to develop their skills.
23. Everyone has the right to work for a fair wage in a safe environment and to join a trade union.
24. Everyone has the right to rest and leisure.
25. Everyone has the right to an adequate standard of living and medical help if they are ill.
26. Everyone has the right to go to school.
27. Everyone has the right to share in his or her community’s cultural life.
28. Everyone must respect the ‘social order’ that is necessary for all these rights to be available.
29. Everyone must respect the rights of others, the community and public property.
30. No one has the right to take away and of the rights in this declaration.
The South African Human Rights Commission (SAHRC)

The South African Human Rights Commission was established by the Constitution, and is governed by the Human Rights Commission Act (No. 199 of 1994). The SAHRC’s mandate is to promote, protect and monitor human rights in South Africa.

It is possible to file a complaint at the SAHRC by telephone on (011) 484-8300 and ask for assistance in filing a complaint. A staff member of the SAHRC will assist in completing the complaint form.

The Equality Courts

The Equality Courts are established by the The Promotion of Equality and Prevention of Unfair Discrimination Act, 2000 (Act 4 of 2000). There are equality courts in all nine provinces. The courts seek to achieve the quick and informal processing of cases, which enables participation by the parties to the proceedings, and also seeks to ensure access to justice to all people. Cases can run concurrently (at the same time) as criminal cases.

The Act allows for cases to be brought before the equality courts that relate to harm suffered due to unfair discrimination, hate speech and/or harassment. The prohibited grounds for discrimination are the same sixteen grounds specified in Section 9 of the Constitution, plus similar (“analogous”) grounds that the court rules to share the same demeaning characteristics as the listed grounds.

For further information on the Equality Act or the Courts, contact (012) 315-1683 or refer to http://www.doj.gov.za/2004dojsite/eqact/eqc_main.html

Forms for complaints can be downloaded at: http://www.doj.gov.za/2004dojsite/eqact/eqc_forms.htm. You can also contact (012) 319-4001.

The Public Protector

The Public Protector investigates complaints about government officials such as pension payout clerks. Complaints about government officials should be sent to the Public Protector who will decide if it is a complaint that requires investigation, try to resolve the complaint, or refer it to someone who can do so.

The telephone number for the Public Protector is contact (012) 322-2916 or 0800 112040

Commission for Gender Equality (CGE)

The Commission on Gender Equality investigates and challenges laws, practices and customs that discriminate against people because of their gender.

To contact the Commission on Gender Equality, contact (011) 403-7182.

Independent Complaints Commission (ICD)

The ICD investigates cases of alleged violations of human rights by the police.

To contact the ICD, call (012) 339-1554.

The Commission for Conciliation, Mediation and Arbitration (CCMA)

The CCMA assists people who have been subjected to an unfair labour practice or whose labour rights are violated. All cases on disputes and discrimination are dealt with by the CCMA.

The CCMA can be contacted at (011) 377-6650.

The Legal Aid Board

The Legal Aid Board provides lawyers to people who cannot afford them and who qualify for legal aid. They do this in many different types of cases, including in criminal cases. This Board has offices at all Magistrate’s Courts.

The Head Office for the Legal Aid Board is (012) 481-2700.
Legal Aid Clinics

Most universities have legal aid clinics to help people who cannot afford a lawyer. University legal aid clinics usually cover only certain areas of law. Contact the University in the area to determine what areas they cover.

Non-governmental organisations, community-based organisations and paralegals

There are many NGOs, CBOs and paralegals in South Africa. They may be able to help or refer a person or organisation that can assist. For example, the following organisations are helpful for matters dealing with human rights abuses and violations:

- Black Sash: (011) 834-8361
- Lawyers for Human Rights: (012) 320-2943
- Legal Resources Centre: (011) 836-7901

Complaints against medical doctors

To make a complaint against a medical doctor, contact the South African Medical Association (SAMA) and the Health Professions Council of South Africa (HPCSA).

The South African Medical Association is a professional association of doctors, which doctors can join voluntarily (this means that not all doctors will be a members or SAMA, so it is important to see if the doctor that is being complained about is a member before approaching SAMA for help). To file a complaint about a doctor, put all the facts in a letter and fax or post it to SAMA. It is important to include contact details so that SAMA is able to contact the complainant.

To contact SAMA, call (012) 481-2000.

The HPCSA is a statutory body that governs health professionals who are members of the Council and it is mandatory for all health care professionals to be a member. To file a complaint, send an affidavit setting out all of the details of the complaint against the doctor or other medical professional.

The HPCSA can be contacted at (012) 338-9300.

Complaints against nurses

All nurses are registered with the South African Nursing Council (SANC), a statutory body. SANC can discipline its members, investigate complaints, and if necessary, hold a formal enquiry. To file a complaint, send an affidavit including all the important details about the complaint, the nurse and details of the incident.

It is possible to contact SANC on (012) 343-0121.

Section 8

8. Case studies

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In the community

Discrimination

Johan is attending University. Last year he lived on campus in residence. However, this year he has moved and lives close to University. It is a nice flat, and he is happier here than he was in residence. Johan has signed a one-year lease, which was the one and only time he has seen Eben, his landlord. Johan finds that there is a big problem with the plumbing in the kitchen and asks Eben, his landlord to please fix it as soon as possible. They make arrangements for Eben to come one day when Johan is in classes.

A few weeks later, Eben asks Johan to vacate the flat. When asked, he indicates that his sister will be coming to live there, which is why he needs Johan to leave. Johan suspects this is not true, and his neighbour tells him that the day that Eben came to fix the kitchen, Eben was complaining about the ‘moffie’ that was living there, and that he would have to get the flat fumigated because it was probably full of AIDS.

Blame, isolation and judgement

Joan is 16 and lives with her parents and three siblings. One day when Joan was walking home from school with her younger brother, and a friend, Seba, the children were attacked and raped by a group of strangers. Joan heard her brother screaming and crying for help, she wondered what the strangers were doing to him, she did not think he was being raped as she was told at school and at home that rape does not happen to boys, that only girls get raped.

This is what followed: somebody heard the screams and called the police, statements were taken, the children’s parents were called in and the three young people were taken to hospital and treated for shock and minor injuries and discharged soon after. None of the parents wanted to talk about the matter. Joan and Seba both agreed that they would not tell their parents about the rape as they might be blamed for the rape. They did not want to talk about what might have happened to the younger brother, all three of them avoided the subject, the boy seemed shaken but he put on a brave face.

One of the nurses from the hospital lives in the same area as the children; she started talking to other people in the community about the incident. A lot of rumours went around the community. One day the two girls decided to go to the clinic because Seba started feeling unwell. The nurse at the clinic insisted that Seba take an HIV test: her reason was that children should not have been so careless and put themselves at risk by walking home, because of course they would getting themselves raped by strangers who might be HIV positive.

The girls went back home and never visited any health care facility again. Seba’s condition got worse and her parents sent her to their relatives in their rural area, where she was neglected and locked up in a room.

On the other hand Joan’s brother could not cope with the teasing at school and the gossip in the community, and he committed suicide. Joan got depressed and unwell, despite the fact that her family tried to give her support, especially after her brother’s death. She refused to go for counselling, and she died within two months of being ill.
Case Study: Positive Management

Senior Operations Manager living with HIV, takes a leading change management role in a large multi-national company.

Alan is a District Manager, for a company that employs just fewer than 9000 staff in the hospitality sector. Alan has been living with HIV since 1997 but had not disclosed this fact to family or friends because he felt guilty and feared discrimination and rejection from colleagues and family.

The company had set up an HIV/AIDS Committee in the workplace, which Alan chaired until 2000. Alan got to a point in his life where he felt he would be affective in the HIV/AIDS committee if he had disclosed his status; He disclosed his status on AIDS Day, 1 December 2000. Contrary to his fears, he got a lot of support from his colleagues, workforce unions and from the company. Alan’s disclosure provided the Board of Directors of the company with a momentum to set up more structures to address HIV and AIDS within the company.

In January 2001, the Board of Directors of the company appointed Alan as the Group National HIV/AIDS Manager; a post intended to lead the fight against HIV/AIDS within the company. Alan heads a team of ten HIV committees with 300 peer educators. A policy was passed in the company requiring each business unit to budget for HIV/AIDS costs and furthermore to report on HIV/AIDS in all regular financial management reports. Alan is responsible for contextualising HIV/AIDS and design the programme implementation strategies relevant to the business demands.

Having a manager who is openly living with HIV at the helm has greatly assisted them in addressing HIV and AIDS within the company. On the other hand Alan has found it easier to disclose his HIV-positive status to family and friends.

Alan does not believe that he is ready to take anti-retroviral therapy. He has maintained his CD4 count above 500 since 1999 with particular attention to lifestyle, nutrition, vitamin supplements and psycho-social therapy.

His strongest role in a senior position as a person living openly with HIV is one of credible advocacy for change and tolerance and the management of HIV and AIDS in the workplace and personal life.

Workplace

Discrimination

Palesa has finally graduated from University and has been shortlisted for the job of her dreams. She has been to two interviews already, and now her potential employer has asked her to take a medical with the company’s doctor, which she is told is just ‘a formality’. Palesa shows up for her appointment, and has her examination. During the course of the examination, the nurse takes a blood sample. Palesa is unsure of what it is for, but does not ask why a blood test is necessary. Later in the week, Palesa is told that she did not get the job. She is unsure of why and what she should do, although she thinks it has to do with her HIV status. The company will not give her any reasons.
Faith-based organisations

Isolation and moral judgement

A member of an HIV/AIDS association who was a very active member in their parish, disclosed her HIV-positive status in her church. She was excluded from church activities after she went public about her status. The reason for this exclusion was that she was ‘living in sin’.

In the same church, the pastor requested a woman who is living with HIV to publicly confess her sins before the congregation.
## Section 9

### 9. Resources and references

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Organisations

The POLICY Project
PO Box 720
Rondebosch
7701
Tel: (021) 685-4894
Fax: (021) 685-6297
E-mail: admin@polproj.co.za
Website: www.policyproject.com

The POLICY Project website addresses HIV/AIDS policy formulation, advocacy, community mobilisation, strategic planning, capacity development, networking, human rights and gender equality. A list of publications is also provided.

The Centre for the Study of AIDS
University of Pretoria
Pretoria
0002
Tel: (012) 420-5876
Fax: (012) 420-4395
Email: csa@up.ac.za
Website: www.csa.za.org

Faith-based organisations

Websites

http://www.anglicancommunion.org/special/hivaids/index.htm

The site provides the vision statement of the Anglican Church regarding HIV/AIDS. There is also a strategic plan for HIV/AIDS ministry and an outline of six key areas of concern, including leadership, care, prevention, counselling, pastoral care, and death and dying. A template for strategic planning in the church is provided.

http://www.christian-aid.org.uk/

This website outlines Christian Aid’s Stop AIDS Campaign, and also provides a range of resources for campaigning for change.

http://www.sacbc.org.za

The website of the Southern African Catholic Bishops’ Conference outlines the Catholic Church’s response to the pandemic, and about 100 AIDS-related activities in Southern Africa which are funded by the Church.

http://www.wcc-coe.org

The World Council of Churches site provides useful details of the council’s stand against stigmatisation of PLHA, pastoral care to PLHA, and educating churches about HIV/AIDS.

Resources and references

Resource pack – To reduce stigma related to HIV and AIDS
Workplace

Websites

http://www.ilo.org
The website provides details of the International Labour Organisation’s Code of Good Practice on HIV/AIDS and the World of Work (including programme guidelines and a code of practice). It includes mitigation of the impact of HIV/AIDS on work, care and support of infected and affected workers, and elimination of stigma and discrimination. It also provides a clear argument as to why AIDS needs to be considered a workplace issue.

http://www.labour.gov.za
The site provides access to the Department of Labour’s Code of Good Practice on Key Aspects of HIV/AIDS and Employment. The document includes a list of principles, and information on workplace policy, confidentiality of HIV status, disclosure issues, occupational benefits and managing risk.

http://www.doh.gov.za
The website, run by the Department of Health, provides access to HIV/AIDS and Sexually Transmitted Diseases in the Workplace, published in 2000. The document outlines policy on issues such as confidentiality, recruitment principles in relation to HIV/AIDS and workplace injuries.

http://www.dpsa.gov.za
The Department of Public Service and Administration website provides access to the comprehensive and exhaustive 158-page document entitled Managing HIV/AIDS in the Workplace: A Guide for Government Departments.

http://www.undp.org
The website of the United Nations Development Programme outlines the Greater Involvement of People Living with HIV/AIDS (GIPA) principle, and the unique contribution that PLHA can make to workplace and other programmes. It provides contact details for organisations wishing to utilise the GIPA principle.

www.sabcoha.co.za
This site is run by the South African Business Coalition on HIV and AIDS (SABCOHA) and Metropolitan. The site provides strategies to deal with HIV and AIDS in the workplace, case studies, and the latest surveys and articles delving into AIDS in the business arena.

DPSA
22nd floor, Batho Pele House
C/O Vermeulen and Van der Walt Streets
Pretoria
Private Bag X916
Pretoria
0001

www.sabcoha.co.za
This site is run by the South African Business Coalition on HIV and AIDS (SABCOHA) and Metropolitan. The site provides strategies to deal with HIV and AIDS in the workplace, case studies, and the latest surveys and articles delving into AIDS in the business arena.

DPSA
22nd floor, Batho Pele House
C/O Vermeulen and Van der Walt Streets
Pretoria
Private Bag X916
Pretoria
0001
The media

Websites

http://www.aidslegal.co.za
The website provides access to the Training Manual for Southern African Media and Communication, published by the AIDS Law Project at the University of the Witwatersrand.

www.sanef.org.za/saef
The website provides information on the work of the South African National Editors Forum as well as the work of the Southern African Editors Forum.

http://www.journ-aids.org
The Cadre website provides the Ethical Guidelines in Reporting on HIV and AIDS for South African Media, which outlines the rights of PLHA, including confidentiality, informed consent, responsibilities of media practitioners, how to interview PLHA, and using language sensitively.

Cadre
7 Prince Alfred Street
Rhodes University
Grahamstown
PO Box 94
Grahamstown
6140
Tel: (046) 8553

http://www.genderlinks.org.za
The Gender Links site provides access to a gender, HIV and media training manual for anyone involved in media work, which highlights the links between gender and HIV transmission.

Gender Links
1 Ernest Oppenheimer Street
Lakeside Place
Bruma
Johannesburg
Tel: (011) 622-2877
Fax: (011) 622-4732

http://www.ilo.org
The website provides details of the International Labour Organisation programme on HIV/AIDS and the world of work, including programme guidelines and a code of practice. A comprehensive training manual is also provided.

http://www.law.wits.ac.za
The website has the 1992 agreement on HIV/AIDS and employment, including details on the rights of employees, workplace testing, confidentiality, managing HIV illness, occupational benefits, risk management and victimisation.

http://www.labour.gov.za
The website has the 1999 Code of Good Practice on Key Aspects of HIV/AIDS and Employment. The code incorporates a workplace policy providing for a non-discriminatory work environment, and provides details on confidentiality, testing, disclosure, occupational benefits and managing risk.

http://www.dpsa.gov.za
The Department of Public Service and Administration website provides access to the comprehensive 158-page document entitled Managing HIV/AIDS in the Workplace: A Guide for Government Departments.
General resources

**www.alp.org.za**
This website provides practical information on how to protect rights, as well as general information of issues related to HIV and AIDS and Human and legal rights. The site also provides a number of publications.

**AIDS Law Project**
Centre for Applied Legal Studies
University of the Witwatersrand
Private Bag 3
Wits 2050
South Africa
Tel: (011) 717-8600
Fax: (011) 403-2341

**http://www.tac.org.za**
The website run by the Treatment Action Campaign provides up-to-date information on all aspects of treatment, including the use of antiretroviral drugs.

**http://www.unaids.org**
This UN website provides a comprehensive overview of the HIV/AIDS pandemic, including global and national statistics, fact sheets and a range of articles on stigma.

**http://www.policyproject.com**
The POLICY Project website addresses HIV/AIDS policy formulation, advocacy, community mobilisation, strategic planning, capacity development, networking, human rights and gender equality. A list of publications is also provided, including all Siyam’kela publications.

**www.repssi.org**
This website is still under construction. Regional Psychosocial Support Initiative (REPSSI) works with children addressing psychosocial issues for OVC as well as HIV related stigma through play therapy and other forms

**REPSSI Secretariat**
Atlas Office Park 1st Floor
372 Oak Avenue
Ferndale
Randburg
South Africa
Tel: (011) 998-5820
Publications


Examines the nature and causes of stigma, explores its effect on the management of HIV and AIDS and suggests possible interventions.


Focuses on the rights of PLHA, gender and HIV/AIDS, rights of infected and affected children, language, and rights and responsibilities of media practitioners, and implementation and monitoring.


Provides an in-depth and extremely useful analysis of HIV/AIDS stigma from a theoretical point of view and suggests a framework for action.


Includes a brief overview of the basic rights of HIV-positive employees, information on the transmission of the virus, and a short checklist of good practice for employers.


Provides guidelines relating to HIV/AIDS policy and planning, workplace HIV/AIDS programmes, and reporting, monitoring and evaluation. It also contains a list of references, contacts and useful websites.


Explores community-based and focused interventions around HIV and AIDS.


Provides practical tips on how to integrate HIV/AIDS responses to existing social, financial and occupational systems.


Presents indicators of stigma developed through a thorough research process – a very useful guide for researchers and programme developers.


The media scan provides a context for the Siyam’kela fieldwork, so that the reader has a snapshot view of how HIV/AIDS was portrayed in the popular television, radio and print media in South Africa at the time that the field research was undertaken.


Proposes indicators for measuring internal and external HIV/AIDS stigma. Highlights the indicator’s relationship to existing stigma, suggesting methods for verification in different contexts and listing conditions for use of the indicators.


Provides a theoretical understanding of the origin and manifestation of HIV/AIDS stigma and highlights the challenge for a stigma-mitigation process.

Describes best practices in stigma mitigation identified during the Siyam’kela Research Project fieldwork from: the faith-based response to HIV/AIDS, media reporting on HIV/AIDS, particularly the relationship with people living with HIV/AIDS, and national government departments as workplace environments.


Includes practical guidelines and strategies for effective reporting on HIV/AIDS issues.


The document recognises “that people living with and affected by HIV/AIDS should share the lead and responsibility in responding to the epidemic, while encouraging society to create the space for them to play this role”. It emphasises empowerment and leadership and is a guiding principle that should be applied to all elements of the HIV/AIDS epidemic. It is based on the recognition that “no community, government or institution can alleviate the impact of HIV/AIDS without embracing those infected or affected”.


This is one of a series of booklets funded by USAID which aims to guide the media sector’s response to HIV/AIDS. These booklets are available from HEARD – the Health Economics AIDS Research Division of the University of KwaZuluNatal.


Reports on a study on stigma and human rights in a community near Pretoria, South Africa, and makes recommendations for interventions.
Training resources used for the Stigma Resource Pack


10. Acknowledgements
We would first like to acknowledge the United States Agency for International Development (USAID) who funded the Siyam’kela Project through the POLICY Project. The Stigma Resource Pack (SRP) was a key output of the Siyam’kela Project of the Centre for the Study of AIDS (CSA).

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Finally, we are deeply grateful to all the organisations and sources (listed in Section 9) from whom material and ideas were drawn – we hope we have done justice to your creativity and hard work.