Guidelines for
Reducing stigma and discrimination and
enhancing care and support
For people living with HIV and AIDS

by Training and Research Support Centre
(Zimbabwe)

Naira Khan, Rene Loewenson

Commissioned by SANASO
with support from the European Commission

Harare, November 2005
This document provides the guidelines commissioned by SANASO from Training and Research Support Centre (TARSC) Zimbabwe. The document is a final version incorporating inputs from a stakeholders meeting convened by SANASO on 25-26 October 2005. The meeting brought together members of faith based organisations, union and workplace representatives, organisations of PLWHA and media.
1. Background

More than two decades have lapsed within which time the battle to improve the life of People Living with HIV and AIDS (PLWHA) has been marked by the advance in understanding of the epidemic and how to prevent its spread and treat its consequences, and by important steps to implement this understanding in service outreach. There do however continue to be numerous barriers to access to these services in Africa, including the negative effects of stigma and discrimination. Stigma and fear of discrimination have been found to negatively influence many community responses to the epidemic. If HIV is determined (or suspected) to be the cause of an illness, family and community members are reported to be less willing to provide care and support\(^1\). The response to such fear and stigma has often been awareness activities aimed at both victim and perpetrator of stigma. These activities have sought to change attitudes towards groups who are being stigmatised and to the disease. However the fact that stigma persists indicates that a more structural understanding of its causes needs to be built and that responses need to address determinants of stigma at their different levels.

Despite repeated programmatic and policy interventions to confront stigma, we are thus still left with fundamental questions to unravel including:
- What is stigma?
- What are the causes of stigma and discrimination?
- Why does it persist despite increasing knowledge and awareness about HIV and AIDS?

The term stigma originated in ancient Greece where slaves and criminals were branded to show that they were outcasts. Stigma can be experienced internally (self stigma) or externally (discrimination). Internal stigma can lead to a person’s unwillingness to seek help or access resources. External stigma can lead to discrimination based on one’s perceived or actual HIV-positive status or on ones association with someone else with perceived or actual HIV-positive status.\(^2\) Thus stigma can be seen as negative thoughts or prejudices about people from particular groups or with certain characteristics.\(^3\) With respect to the HIV and AIDS pandemic, stigma is an enormous hurdle, which intrudes at all levels of prevention and intervention. For example, stigma insidiously interferes with programmatic efforts at an institutional level where employees may not utilize

---


benefits or resources in place to assist persons living with HIV and AIDS, health workers may find it difficult to treat people and to assist them in managing and coping with the situation. On a personal level, stigma may mean loneliness, abandonment, ostracism, violence, starvation and death. In summary, the effects of stigma on individuals and the community include:

- Emotional stress and anxiety, depression, attempted suicide, isolation;
- Problems in family relationships and friendships;
- Increased inequities between those who are affected and those who are not;
- Increased disability;
- Concealment of the disease after diagnosis, leading to stress and anxiety;
- Poor prognosis;
- Participation restrictions (e.g., loss of job, economic dependency, inability to marry, lack of access to loans and credit) that may affect entire families and, in high prevalence areas, entire villages
- Isolation;
- Increased psychological and psychiatric morbidity;
- Lack of motivation to continue treatment
- Empowerment (e.g. positive self-image and confidence) developed in resistance to discrimination (through participation in support groups for people living with HIV and AIDS).

Due to the issues that individuals suffer as a result of stigma, it is found that one of the biggest repercussions is the negative effect on health care interventions. Individuals often wait too long to access health care facilities and this may impact negatively on both the individuals’ health and the community as a whole. Some of the consequences of this factor have included:

- Delays in presentation for treatment leading to prolonged transmission of the disease in the community;
- Poorer treatment prognosis; more complicated and more expensive treatment;
- Continued transmission of HIV
- Poor adherence and default on treatment;
- Risk of drug resistance;
- Increased burden on health services;
- Negative image of health program.

Research has provided some insights into the complexities of the issues. With respect to causes, some of the major ones, which have been highlighted, include incomplete knowledge, fears of death and disease, sexual norms and a lack of recognition of stigma.\(^4\)

---

Insufficient and inaccurate knowledge combines with fears of death and disease perpetuate beliefs in casual transmission and avoidance of those with HIV. (Page one)\(^5\)

Another major cause is the knowledge that HIV can be transmitted sexually immediately conjures up scenarios of immoral behaviour resulting in PLWHA being further stigmatized. Another important factor which was found in the above research was that the majority of people in their three country research expressed concern and compassion for those persons who are affected and infected by HIV and AIDS but simultaneously expressed words and actions that are stigmatizing. For example:

One cannot be blamed because this disease is just like malaria nowadays, it is everywhere and everyone is committing adultery…We will not isolate this person if she or he comes back home because he didn’t want to settle…the father may step out of the family just once and get the disease then bring it home to his wife. (Participant in an FGD of rural women, Tanzania, page 22).\(^6\)

This participant is sending mixed messages: she is showing her compassion and also stigmatising PLWHA by using stereotypic beliefs that people who commit adultery are those that contract the virus.

However stigma is not simply a psychological response. It is also a means to responding to disease without challenging the conditions that cause it. A process takes place within communities where differences are labeled, given negative attributes, where the people are characterized as separated from the community (‘us from them’), causing loss and discrimination. Society needs to explain or control disease, and if flight from disease is not a realistic option, then blaming the victim is one response used as people seek to isolate and distance themselves from the problem. The negative impact of such a response is to make stigmatised people responsible for taking action on their affliction, rather than society as a whole. This can leave the underlying structural causes of the disease untouched, as has been the case with females or adolescents. Stigma is thus a way of sustaining power relations, despite the powerful force that disease can be to confronting them. Groups already ‘scapegoated’ for other reasons, including migrants, commercial sex workers, poor women, are more vulnerable to such stigma. AIDS related stigma plays into and reinforces class, gender, sexual and racial inequalities in society. This dissonance between social norms and reality undermines the support stigmatised people get from society\(^7\).

\(^5\) Ibid.
\(^6\) Ibid.
Socioeconomic status, age and gender are thus found to be factors that contextualise the experiences of individuals with respect to stigma. For example, poor people may face greater stigma because they have less money and resources to hide their status. Women may be blamed more than men as their infection with HIV challenges the standard family and reproduction-oriented sexual morality found in most societies. In the context of these norms, commercial sex workers are seen as the agents of infection and their clients as unwitting victims.

These and other factors that have made the reduction of stigma a challenge to in the majority of environments and in particular in Southern Africa. Many of the above factors lead to self-stigmatization, involving feelings of guilt and fear among infected persons.
2. The guidelines

This document aims to provide guidelines on HIV and AIDS stigma reduction strategies for use by non-governmental organizations and the communities that they work with.

The guidelines cover four thematic areas:

i. Stigma and the family;
ii. Stigma in faith based organizations;
iii. Stigma in the Workplace;
iv. Stigma and the Media/communication.

The guidelines have been developed to contribute information to support organisations working to achieve the following results:

- Reduce stigma and discrimination in the family through attitude changing education that enhances care and support for people living with HIV and AIDS.
- Broader and increased involvement of Faith-based organizations in the fight against HIV and AIDS, in order to contribute to the reduction of HIV/AIDS prevalence, and the restoration of positive values in society.
- Create a workplace environment that encourages prevention, treatment and care, promotes voluntary counseling and testing and is supportive to all workers irrespective of their HIV and AIDS status.
- Increase the capacity of national networks to use the media and media personnel and all forms of communication in raising awareness and promoting action to challenge HIV and AIDS related stigma and discrimination.

2.1 Using the guidelines

The guidelines were developed by reviewing good practices on stigma and discrimination in sub-Saharan Africa with the objective of providing a format which may be utilized by partners to plan intervention programs to suit their various environments. The rules or processes outlined in these guidelines have appeared to work in other environments or countries and are a useful starting point for new programs. They can also be used to review existing programs to determine whether they adequately deal with stigma as an issue.

The guidelines provide the basic template or stencil and it is up to the program planner to use them to suit the intervention required. It is important for organisations that are planning interventions to note that the impact they have on reducing risk will demand a coordinated, comprehensive and multisectoral response to stigma that addresses the different environments where people live and work. There is little point, for example, in having a workplace program which
is very successful in reducing stigma and then letting employees return to a community that stigmatises them or attempt a church where they are called sinners. All possible environments should be covered and partners in the area should try as much as possible to coordinate programs. In other words, if one organisation works with the media and another only has resources to work with workplaces etc, look for gaps and then intervene. This co-ordination may avoid resources being wasted in duplicating existing programs and ensure that different environments are addressed and that all organisations and communities play a coordinated role in reducing stigma associated with HIV and AIDS.

Program implementers should thus be aware of the areas raised in these guidelines and trained in options to address stigma raised in the guidelines before beginning interventions.

In using these guidelines the role of PLWHA is central. As in any activity related to HIV and AIDS, understanding current situations, designing interventions and planning responses to HIV and AIDS calls for involvement of PLWHA in the various stages outlined in a meaningful way. Participants to the October 2005 SANASO meeting reviewing these guidelines noted that programmes for the ‘Greater Involvement of PLWHA’ (GIPA) should be known as the GEIPA program - Greater Empowerment and Involvement of People living with HIV and AIDS.

2.2 Lessons from previous experiences

There are some general lessons learned from prior interventions that have had some

i. Understand the underlying factors producing stigma, integrate action on these into programmes wherever possible including participatory reflection and action in and by the communities concerned. In other words, before beginning an intervention it is very valuable process to involve the communities in identifying the issues and problems and possible solutions. This is known as the participatory reflection and action (PRA) approach whereby researchers or developers use various techniques to listen more closely to community voices and to address the need identified by the target population, rather than applying a predetermined notion of community needs. Various tools can be used for PRA processes as points of discussion.

ii. Involve people living with HIV and AIDS in program interventions at all levels- community, district and national level. Their involvement should also extend to policy development, research and evaluation.

---


iii. Mainstream HIV prevention, care, treatment and support activities into existing programs and facilities where possible.  

iv. Be aware of gender issues at all levels of interventions.  

v. Address stigma at levels where it arises or where it can be acted on in communities, including workplaces, media, recreational facilities, schools, churches and in faith-based organizations. Ensure that people are not exposed to contradictory environments, and that where they are this is identified as a social problem and not an individual problem. For example, an individual who has disclosed their status to their family may find it difficult to do so at a workplace where an organization has not mainstreamed HIV and AIDS into the organizational activities and policies.  

vi. Promote complementary action on stigma at the level of individuals, families, social groups, organisations and at national level. For example awareness activities aimed at women as a social group may need to be complemented by activities that promote communication between couples, and by an organization of services and laws that reinforce these actions.  

More specific focus is given in sections 3-6 on guidelines for dealing with stigma in the four areas outlined above, viz:  

i. Stigma and the Media/communication.  

ii. Stigma in the Workplace;  

iii. Stigma in faith based organizations;  

iv. Stigma and the family;  

2.3 Useful reading materials  

- Maseru Declaration on HIV and AIDS (SADC, 2003).  

---  

12 By the end of 2000, 55% of infected adults in sub-Saharan Africa were women. Teenage girls in sub-Saharan Africa are infected at a rate five or six times higher than teenage boys. UNIFEM, 2001. Turning the Tide.  
15 Ibid.  
16 Issues arise at these different levels: for example: Are the laws and policies at the national level and organizational level recognizing the rights of PLWHA? Are there effective policies in place to enforce prevention, care and treatment activities for those infected and affected by HIV and AIDS? At organizational level, is staff trained? Are there opportunities for factual information sharing, individual and group counseling? Do employees know what policies and procedures exist within organizations for accessing resources for treatment? Are the organizational policies with respect to PLWHA accessible? Are the procedures for obtaining benefits supportive, confidential and quick?


3. Media guidelines

The power of the media cannot be underestimated. We have witnessed the role the media plays in providing information and influencing social change. In Africa, despite variable levels of literacy and access to print information and highly unequal access to digital media, there has been a growth in the number of TV stations, radio stations, satellite television and internet. The role of the media in combating the HIV epidemic has not been fully assessed. Past research has found that the greater access Africans have to the media and to accurate information about contraception, the more likely they are to use family planning techniques. However the other side of the coin was also revealed when uncritical media reporting of the supposed AIDS treatment with Kemron in the late 1980s influenced people into believing that AIDS was not a problem and dampened responses.

3.1 The role of the media in the fight against HIV and AIDS

Looking back over the last two decades to responses to the HIV and AIDS pandemic, three variables emerge repeatedly as major contributors to successful interventions.

- Strong political commitment as demonstrated by the example of Uganda where people were provided with an environment that allows them to discuss their issues without fear and they are given the opportunity to be part of the process for interventions and solutions.
- An equally strong response from a mobilized and committed civil society.
- An engaged and strong media, which facilitates all the communications at all levels of society.

There are five aspects of the role of the media, which are outlined below in the quest to eradicate HIV and AIDS.  

i. The provision of correct and accurate information about modes of transmission, prevention, treatment and care.

ii. A tool for communicating community responses and concerns to policy makers and international audiences. The media has the power to take the smallest, poorest and most marginalized voices so that they are heard.

iii. The media play a key role in holding politicians accountable for the use of funds and the program responses to the pandemic.

iv. Media may challenge governments to provide treatment, care and support for people living with HIV and AIDS.

---


v. The most important role of the media is to humanize and normalize HIV and AIDS and take it from the status of disease to a day-to-day reality of our lives. Media portrayal can have an enormous contribution to stigma and discrimination. We only have to recall the days when HIV and AIDS was portrayed as an alien western disease associated with a particular lifestyle or as the ‘gay plague’.

3.2 An Ethical Approach to HIV and AIDS Reporting

An ethical approach to a subject is the one intended to result in least harm and greatest good. An ethical approach to HIV and AIDS, whether from the media, the medical profession or the public at large aims to achieve a reduction in numbers of people infected with HIV, access to effective treatment for AIDS and supportive responses to mitigate the consequences of AIDS on individuals, families and communities. Ethics apply to all workplaces equally but the media has more influence. Thus informing of the status of an individual in the media has more far reaching consequences than if a doctor revealed it to another doctor. Reporting on HIV/AIDS is very challenging due to the numerous variables, which may contribute to shaping the final copy. Variables, which may ultimately detract from the important issues at hand and may include:

- Editor or sub-editor recommends a sensationalist, negative view;
- Audiences bored or in denial of the subject;
- Discussion of sexual matters may be censored;
- Distrust of media by politicians, NGOs and international agencies.

Reporters themselves may hinder good reporting by not spending enough time researching and investigating various viewpoints and by being misled by overoptimistic press releases which are totally removed from the reality of people’s lives. Reporters can also be influenced in their writings by their own personal biases and attitudes. For example, they may distrust spokespersons for PLWHA as wanting to attract money or male reporters may have the attitude that violence against women is justified under certain circumstances. Below are some guidelines, which may assist media personal to avoid confusion and poor reporting on the topic of HIV and AIDS.

Confidentiality

Ethical reporting of HIV and AIDS requires that the confidentiality of those with the virus and their family and friends, be respected. Identities and addresses should not be revealed or hinted at without their permission and reporters should not pressurize people with HIV into revealing their identities. Information given in confidence should never be passed and made accessible to others, inside or outside the media.19

Using Language that does not communicate stigma
Ethical reporting of HIV/AIDS requires that the media use language and ask questions that reduce or avoid stigma and where possible, reduce or avoid reporting the negative attitudes of others to the disease.

The use of language has been found to be a very important means to molding and reflecting our attitudes. Words often carry emotions that encourage a positive or negative response. The response the reporter receives may not be the one wanted, thus it is recommended that the language used be as far as possible, neutral of emotion. The following principles are recommended by the United Nations Development Program (UNDP) in their guidelines for reporting HIV/AIDS:

- Language that is inclusive and does not create or reinforce a ‘them/us’ mentality;
- Vocabulary drawn from peace and human development rather than war;
- Descriptive terms preferred by the persons themselves. For example, ‘sex worker’ or ‘women in the sex trade’ is preferred to ‘prostitute’.
- Language that is value neutral, gender sensitive and empowers rather than disempowers.

Treatment and ‘cures’
Ethical reporting of HIV and AIDS requires that all claims of effective treatment, from whatever source, be subject to scrutiny, balance and reported uncritically. Balance means giving due weight to the story and covering all aspects, including media, social, political, economic and other issues. Balance also means highlighting positive stories where appropriate, without underplaying the fact that HIV and AIDS is a serious crisis.

Misconceptions
Ethical reporting of HIV and AIDS requires that media professionals do not repeat misconceptions or report irrelevant controversies such as the origin of the disease. If members of the public, or experts, are quoted repeating misconceptions, their words should be refuted by corrective quotes from national or international experts.

Investigative reporting
Ethical reporting of HIV and AIDS requires research into and reporting of issues that result in long term improvement in care and prevention. This means that media should be less preoccupied by short term credit to individuals or institutions than by the long term community benefit of what they are reporting. Media should hold decision makers and policy makers accountable for their handling of the epidemic, including government, pharmaceutical industry and advocacy groups.

20 IBID, 9.
Gender
Media reporting on HIV and AIDS need to build an understanding of the unequal relations between men and women that exist in every society and the distorted perspective of the epidemic that result. In reporting on issues, the link between gender and poverty should be explored in analyses of situations. Wherever possible, media professionals should be trained in gender issues and take care to ensure that reports present a perspective, which accurately represents the experience of both men and women. Journalists should be aware of and seek out the gender dimensions of all aspects of the epidemic across the spectrum of prevention to treatment and care, as this will add to the depth and context of reporting and reveal new areas for media attention.

Children
The rights of children have particular importance in the context of the epidemic. Particular care should be taken in reporting on children as they are experiencing the most extreme consequences of the epidemic and their rights to privacy should be afforded even greater protection. The identity of children should be protected and only revealed if the public interests are overwhelming. The latter should only be done if no harm is foreseeable and if they and any parents or guardians have given informed consent. Journalists should ensure that the concerns of children are covered by upholding their right to participate and be heard.

Voices and images of people living with HIV and AIDS
There is need to ensure that the voices and images of people living with and affected by HIV and AIDS are heard and seen in the media. Special care should be taken to highlight the human face of the pandemic, with diverse voices including women, men, vulnerable and marginalized people.

Minorities
Minority groups within a society should be treated with respect in media reporting on HIV and AIDS. Those who are particularly vulnerable to HIV should be described as such and not as potential sources of infection for the broader community.

Sex
Media has a role to play in an open and respectful discussion of sexual issues, taking cultural norms into account but also being aware of where these are positively or negatively linked to stigma. This implies avoiding amplifying those norms that are associated with stigma and reinforcing those that reduce stigma.

3.3 Reviewing stories on HIV and AIDS
In summary, editors and journalists can pay attention to the following issues in reviewing media reporting on HIV and AIDS. These questions were endorsed by the Southern African Editors Forum (SAEF) and Media Institute of Southern
Africa (MISA) to provide guidance to media councils, training institutions and media companies, as well as individual editors and journalists:

i. Are the facts and statistics being cited in context, verifiable and current?
ii. If the article included health or medical claims, has the claim been verified by two or more sources.
iii. Is the health or medical claim in the public interest or can it cause harm
iv. is the article sensitive to traditional and cultural practices
v. Does the language and the images avoid reinforcing stereotypes
vi. Are the headings and captions accurate in their portrayal of the content of the article
vii. Does the article present an independent analytical perspective that takes into account the views of various stakeholders on the issue
viii. Has the journalist disclosed any conflict of interest if receiving gifts or sponsorship from organisations, institutions and corporations
ix. When appropriate are the perspectives of people living with HIV and AIDS included
x. Has the individual given expressed or written consent for the use of their name or picture in the article
xi. Does the article take into consideration the interest and safety of children portrayed in stories?

3.4 Useful reading materials

- Southern Africa Editors Forum (SAEF) (Undated) Guiding Principles for Ethical Reporting of HIV and AIDS &Gender, Mimeo, South Africa

---

4. Workplace guidelines

The workplace is a very important environment within which to address issues of stigma and discrimination. This is due to the fact that the majority of those infected are in their prime productive period. The use of knowledge of a person’s status to discriminate against them with respect to recruitment, promotion and staff development opportunities has been reported across the region. This has consequences for the individual, their family and the workplace. The family will find it difficult to access healthcare, nutrition, shelter and education if the breadwinner loses employment. The workplace may experience direct losses due to lost skills and recruitment costs, but also indirect consequences in worsening industrial relations, loss of workplace trust and job insecurity. This may lead to people avoiding companies that carry out such practices.

To deal with these issues in line with fair labour standards and public health ethics, the Southern African Development community (SADC) and countries in the SADC region have developed a policy and set regulations on AIDS at the workplace that outline fair labour standards. The SADC guidelines on HIV and AIDS and Employment and national regulatory provisions are thus essential background reading for any workplace practitioner aiming to deal with stigma. Further the International Labour Organisation (ILO) has also set up guidelines on workplace practices that provide guidance in this area. These references are cited in the useful reading materials at the end of this section.

Despite the presence of such laws and policies, in the rapidly changing environment with increased labour flexibility, retrenchments and restructuring, many workers are not aware of their rights, many may face discrimination, illegally testing and dismissal because of their HIV status. The role of trade unions in the struggle against the epidemic has been crucial, but also limited and insufficient.

In general, the following strategies have been effective in combating workplace HIV/AIDS related stigma and discrimination.

- A legal framework at national and sectoral level that provides for fair labour standards in relation to HIV and AIDS
- National or sectoral labour market and health services that support the implementation of workplace policies
- Tripartite national mechanisms and bipartite sectoral mechanisms that inform the employer and labour organisations and provide a means for resolving workplace policies on HIV and AIDS
- An understanding of the public health response to HIV and AIDS as integrated within the management of illness generally (eg TB, other chronic conditions) and the role of the workplace within this
• A workplace policy that addresses HIV and AIDS stigma and discrimination as well as mainstreaming HIV and AIDS issues at all levels of the organisation.
• Integrating and employing PLWHA at all levels in the organisation showing that they may be productive for many years if they receive the right support.
• Creating a safe and creative environment for disclosure by providing counseling, care and compassion for workers.
• Systematic education in the workplace that regularly reinforces stigma reduction.
• Provide a suitable exit package across the board for all chronic illnesses.

4.1 Workplace Policy
The International Labour Organisation (ILO) and SADC codes noted above provide guidelines on developing HIV and AIDS workplace policies and programmes using consultation between employers and employees. They stress the importance of involving workers in policy development as it encourages discussion around the issues of denial, disclosure, stigma and discrimination. Also stressed is that stigma mitigation cannot be confined to a single campaign but requires to be integrated into a range of ongoing activities in the workplace. In summary both codes try to address the following issues:

• Elimination of stigma and discrimination on the basis of real and perceived HIV status.
• Management and mitigation of the impact of HIV and AIDS in the workplace.
• Care and support for workers and their families infected and affected by HIV and AIDS.
• Prevention of new infections in the workplace.23

The following are six key components recommended by the SADC code which would form an effective workplace policy.

1. **Information, Education and Communication (IEC) programs.** It is recommended that these programs be developed collaboratively between employees and employers and be inclusive of the families of employees.
2. **Job Access.** The code recommends that no direct or indirect pre-employment test for HIV should take place. South African Airways paid a high penalty for discrimination against a prospective employee for being positive. On appeal to the Constitutional Court in South Africa, the case was won by the applicant on the grounds that he was unfairly

---

discriminated against and was medically fit for the job as a cabin attendant.  

3. **Workplace Counseling and Testing.** The following recommendations are made with respect to workplace testing:

- Privacy is the right of all employees and testing should be voluntary and not forced.
- Disclosure, like testing should be voluntary.
- All Medical information should be confidential.
- Disclosure should only happen after the infected person is comfortable with it happening. Disclosure should be done by the infected person and only after written consent has been obtained.
- Safe and supportive plan should be created for disclosure and after.
- If a program is not already in place, it is important to consult workers before VCT is integrated into the workplace as alternative places for provision of VCT within the community may be preferable.

4. **Job Status.** The status of a person should not be a factor in selection, promotion, training and transfer.

5. **Managing illness and job security.** The code states that employees should be entitled to all the benefits available without discrimination. If an employee becomes too ill to perform her/his agreed duties because of AIDS, the standard benefits and conditions and standard procedures for termination of service for comparable life threatening conditions should apply without discrimination.

6. **Protection against victimization.** The code recommends that PLWA should be protected from stigmatization and discrimination by co-workers, employers and clients. It recommends that workplaces have workers committees and staff associations that arrange discussion groups where people can be open about their HIV status and discuss how they coped with the disclosure.

### 4.2 Principles based on good practice on Stigma Reduction at the workplace

The basic principles for reduction of stigma at the workplace are outlined below and are drawn from practices currently being implemented in southern Africa. Workplaces that have implemented successful stigma reduction have:

- Conducted an audit or impact assessment study, in order to assess how the HIV and AIDS pandemic will impact on the organisation.
- Developed a comprehensive HIV and AIDS policy analysis to assess whether policies in place reinforce HIV and AIDS related stigma or not.

---

24 Hoffman v SAA, 2001(1) SA (CC).
For example, the Ministry of Public Service and Administration in South Africa with their Impact and Action Project on HIV/AIDS\textsuperscript{25} developed a public service policy \textit{framework} to guide government departments on minimum standards for the effective management of HIV/AIDS in the workplace. The latter was chosen over the one size fit all policy to allow greater flexibility for policy development.

- Ensured access to basic prevention, treatment and care services within an overall framework of fair labour standards, employee benefits and through consultation and negotiation
- Supported bipartite mechanisms to resolve issues, develop and monitor policies and programmes and promote dialogue on AIDS at the workplace. Bipartite mechanisms involve consultation between employees and management to come to an agreement of how issues and programs are developed and monitored at the workplace.
- Supported the role of PLWHA at the workplace. The Greater Involvement of People Living with HIV and AIDS (GIPA)\textsuperscript{26} programme, for example, promoted visibility and openness of PLWHA to build a workplace environment supportive of PLWHA, to promote positive role models to other PLWHA employees and thus assist to destigmatise the disease. The United Nations Development Program (UNDP) has been advocating for the principle of Greater Involvement of People Living with HIV/AIDS (GIPA) in the workplace. The UNDP declares that;

“\textit{People living with and affected by HIV/AIDS should share the lead and responsibility in responding to the epidemic, while encouraging society to create a space for them to play this role…no community, government or institution cab alleviate the impact of HIV/AIDS without embracing those infected or affected.”}

The GIPA principle has been implemented in many workplaces in South Africa with great success. The success of the model is dependant on a number of factors outlined below.

a) Visibility of and disclosure from PLWHA.. By involving PLHWA, workplace programs have had greater credibility, to have been more likely to address the concerns of employees and finally to motivate stigma mitigation.

b) The ongoing support of management to a workplace HIV and AIDS program.\textsuperscript{27}

c) Messages challenging HIV and AIDS stigma integrated into ongoing communications in the workplace, in order to ensure a long term effect on group attitudes and opinions.


\textsuperscript{26} IBID.

\textsuperscript{27} Ibid.
d) Attitudes to HIV and AIDS influenced through horizontal rather than vertical channels.
e) Support groups for PLWHA employees provided, run by professionally trained facilitators. Support groups should include employees who are infected and affected by HIV and AIDS.
f) A sufficient number of well trained peer educators, with good interpersonal skills and well trained in basic facts to pass on their knowledge to employees.
g) Improved employee benefits, especially for health care, pensions and orphans. In the earlier discussed case of the Ministry of Public Service and Administration of South Africa, employee benefits were improved to assist staff members affected and infected by HIV and AIDS. This included improved funeral benefits, pensions for orphans, restructuring of pensions for spouses, and an extension of the previously narrow definition of spouse for government employees.
h) Monitoring all HIV and AIDS interventions to ensure their sensitivity to stigma and that they do not inadvertently increase stigmatisation.

4.3 Useful reading materials

- Code of conduct on HIV/AIDS and employment in the Southern African Development Community (SADC, 1997).
- Zimbabwe: Labour relations (HIV and AIDS) Regulations 1998
- Implementing the ILO Code of Practice on HIV/AIDS and the world of work an education and training manual (ILO, 2002).
- A training manual for shop stewards on HIV/AIDS in the workplace, (ICFTU-AFRO with technical support from ILO, 2002).

• Workplace HIV/AIDS programs. An action guide for managers (Family Health International 2002). http://www.fhi.org/NR/rdonlyres/esqfd7r6roskwyjn7ccoxzwhzu2fny7pow5qsr2splmyrztzsp2ta2f5z4lahypynxxilfibvoxycb/workplacehivprograms.pdf


• The faces, voices and skills behind the GIPA Workplace Model in South Africa (UNAIDS, UNDP 2002) http://www.unaids.org/NetTools/Misc/DocInfo.aspx?LANG=en&href=http%3a%2f%2fgva-doc-owl%2fWEBcontent%2fDocuments%2fpub%2fPublications%2fIRC-pub02%2fJC770-GIPA-SA_en%26%2346%3bpdf

5. Guidelines for Faith Based Organisations

Faith based organisations (FBOs) are amongst the many institutions in society that shape the values and attitudes that guide responses to illness and vulnerability and that support appropriate and compassionate responses to social changes.

Faith-based organisations (FBOs) are increasingly establishing support initiatives to assist households affected by HIV/AIDS and play a major role in supporting those who are extremely poor. Over 90% of churches and mosques surveyed in a six-country study had activities to support orphans and vulnerable children, extended to community members “on the basis of need and not creed” 30.

Religious beliefs and organisations have provided psychological support and comfort to PLWHA and their families and religious values have been used to encourage non-stigmatising behaviours. One of the often-quoted principles is the one of not judging the behaviour of others based on the premise that it is the role of God to pass judgment, not the role of people. The spiritual comfort provided by faith based organisations has helped to reduce the guilt that PLWHA may feel.

It is however important to note that religious beliefs may also underlie social norms that lead to stigma. For example beliefs that proscribe woman’s roles may lead to stigma against women with HIV and AIDS. Faith based organizations thus have an important role in promoting religious beliefs that confront stigma, and encouraging dialogue on those that do not.

5.1 The role of Faith based Organisations in reducing stigma

Experience from existing work by faith based organizations (FBOs) indicate that they can

- Introduce a new language to talk about HIV and AIDS in a way that reduces stigma and allows PLWHA to feel accepted and integrated into the faith community. For example, groups in South Africa have used traditional religious texts, such as the Bible and Qur’an, in a way that encourages acceptance and care for PLWA. The idea of HIV and AIDS as being a punishment for having sinned is a central issue to challenge and replace with the idea of a compassionate God. 31
- Involve PLWHA at every level of the program. This strategy utilizes the skills and experiences of PLWHA but also allows them to be more visible. This visibility in turn helps to reduce stigma.

---

• Have a common voice among FBOs by forming partnerships. These partnerships allow groups to not only learn from each other but also provide support to each other.
• Address the issue of sexuality and religion. Despite traditional religious taboos on discussing these issues, no adequate response can ignore the sexual dimension given that HIV and AIDS is most often sexually transmitted in Southern Africa.
• There have been difficulties in the past in the issue of condoms and religion and in the response of churches to use of condoms. There may be lessons in dealing with this from the Uganda experience. In Uganda it was found that religious organisations played an instrumental role in raising the countries awareness on HIV and AIDS, not only by promoting abstinence and marital faithfulness, but also by not openly condemning condom use. Anglicanism, Islam and Catholism all have their own rationales for their support or prohibition of condoms. Anglicans in Uganda view condoms as an HIV prevention mechanism, only to be utilized in good Christian marriages. Muslims justify the use of condoms through Qur’anic passages, whereby it is reasoned that the sanctity of life is greater than the sin of condom use. Catholics also value the sanctity of life but see condoms as preventing the creation of life through its function as a contraceptive. In most programs in Uganda the Catholic Church will not comment on or condemn the use of condoms.

Many FBOs have used a two-pronged program, which intervenes at two levels namely theological reflection and practice. In many communities FBOs provide the majority of HIV and AIDS related services such as counseling, education, health care, care for orphans and home based care. Theological reflection has involved discussions on the implications of HIV and AIDS for religions and unpacking the issues around sex and responsible sexuality.

5.2 Guidelines for action by FBOs in reducing stigma

FBOs can utilize Theological Reflection to address stigma, through

I. Studying the texts. The response of any FBO should begin with a sound framework derived from the book of their choice of their response theologically. This will allow those leading the FBOs to challenge traditional notions of sin and blame.

II. Reconciliation. Many diverse and extreme opinions may be apparent in the Church or group and it is important to bring all these persons together with PLWHA in order for them to be reconciled and understand each other better.

---

33 IBID.
III. **Challenging Responsibility.** Important for all groups to make responsibility a communal issue. In other words until all members of the group realize that all persons are responsible for the pandemic, as all lives are affected, stigma will not be addressed. FBOs may intervene for those with less power in society, such as low-income women and adolescent females, to protect them from stigma and to redress the power imbalance that may lead to groups being stigmatised.

IV. **Mainstreaming AIDS and sexuality education.** A systemic method should be determined within a group to integrate discussions of sexuality. For example, one church would have 15 minutes during each church service to discuss HIV/AIDS and sexuality. Members of the congregation found this very useful in that it legitimised the notion of having these discussions at home. If you can talk about sex at church you can even talk about it at home. This allowed families to communicate more openly and begin to break down the barriers to more open communication on matters of sexuality.³⁴

The second component of the FBO program has been to provide palliative care for those who are ill, to have a program to build the capacities of the leaders so that they may respond to the pandemic in a non-stigmatising way. Another important aspect of this level of intervention is to provide some activities with a preventative component.

*FBOs may also play a role in raising awareness and responding to fears.* This involves educating members of the congregation about HIV and AIDS transmission and living positively. FBOs differ in their message with respect to the use of condoms as there is some variability, due to the assumption that it encourages immoral sexual behaviour. Information should also be provided, to reduce fears amongst the membership on transmission of the virus.

Finally, FBOs may run support groups and encourage the full participation of PLWHA at all levels of the hierarchy. It is very important for FBOs to provide a safe place for PLWHA to disclose the status without being stigmatized and to look forward to some help and support from fellow members. In South Africa it has been found that when church leadership disclose their status to other members, impact has been perceived to be very motivating for others in the congregation.³⁵

---
³⁴ IBID.
5.3 Useful Reading Material

6. Guidelines for the family

Stigma within the family or directed towards an affected family is usually the most difficult to strategise for. This is due to the fact that the family has many complex relationships which all come into play when dealing with issues of stigma. By inhibiting open communication, stigma makes disclosure in the family very difficult. Sex and sexuality are already issues that are seldom addressed within the context of the African family, thus, stigma around HIV and AIDS is particularly intense because it concerns the already taboo subjects of sex and death and because the virus is transmitted from one person to the other.36

6.1 Gender Dynamics in the family

Stigma is socially constructed and reinforces existing prejudices in society such as sex workers, persons with alternative sexuality etc. In the family context it is usually women who bear the brunt of the burden of stigma, especially pregnant women and mothers.37 Gender and gender relations are very important variables to consider when strategizing reducing stigma due the following complexities:

- Women are more vulnerable to HIV due to physiological, economic and social factors.38
- Gender is socially constructed and defines women as submissive, monogamous and child bearing and men as dominant, aggressive and sexually promiscuous.39
- Some men who perceive themselves as having been emasculated by unemployment and the erosion of traditional, patriarchal values will resort to sexual violence to feel powerful and male.40
- Women with violent partners and those who engage in transactional sex are more at risk of HIV.41
- Women tested when pregnant are more likely to have knowledge of their status before their partners and are often blamed for infecting him.42

Dealing with stigma within the family thus demands interventions that address gender equity at numerous levels and that increase sensitivity to gender issues.

37 IBID.
39 Ibid.
41 Ibid.
6.2 Children and Youth

Children both stigmatise and experience stigma. One of the most common forms of stigma experienced by children affected by AIDS is teasing and social isolation by peers. This suggests that children absorb the societal attitudes towards AIDS at an early stage and it is very important to include them in interventions at an early stage. A number of child centered approaches have been developed and they have been very successful in the following ways:

- Addressing the culture of silence on HIV and AIDS among children and their families;
- Enabling older children and parents to use their coping skills for survival and development and how to care for younger siblings;
- Supporting older children and parents in providing appropriate care for younger children.
- Enable families to develop coping strategies on the economic impact of HIV and AIDS among children including legal issues, vocational skills and strategies to continue the children’s education.

Child Centered Approaches include the use of memory boxes or books, psychosocial support and life skills training.

- **Memory boxes** are an approach used to help families to come to terms with an HIV positive diagnosis, communicate with their families and prepare for the future. They are like a treasure chest of family photographs, letters, drawings, stories and anything else that holds special significance to remind about the family. It is a way to collect information about the family which would otherwise be lost. Memory boxes or books give parents an opportunity to talk to each other, telling each other how they feel and to talk about the past and the future. These boxes or books enable parents to inform their children of early lives, family origins and relatives. It also allows parents to express their own beliefs, values and aspirations to their children’s future. The box is also a good strategy to begin dialogue, which can lead to disclosure of status. Important issues such as inheritance, financial support and emotional support are usually included in the box by parents as a source of reference for children.\(^{43}\) It is best to make memory boxes when the parents are alive and not sick so that they can think clearly and have energy to answer lots of questions and make it fun. Many memory boxes are made when the parents are sick. This can be very difficult and distressing but can also be a way of saying goodbye.\(^{44}\)

- **Psychosocial Support** is an ongoing process of meeting the physical, emotional, social, mental and spiritual needs of an individual, all of which are considered to be essential elements for meaningful and positive


\(^{44}\) [Planning our future: A booklet for families and communities. Safaids and JSI (UK), 2004.]
human development. Important that all are done within the cultural beliefs and rituals of the person.

- **A Life Skills Approach** is an interactive, educational method that not only focuses on transmitting knowledge but also aims at shaping attitudes and developing interpersonal skills. The primary aim of the life skills approach is to enhance young people’s ability to take responsibility to make informed choices and avoid risk-taking behaviour. Teaching methods are youth centered, gender sensitive, interactive and participatory using methods such as role playing, debating, story telling and discussions. Evaluations of life skills programs have indicated that programs that include sexual and reproductive health information have proven to be effective in delaying the onset of sexual intercourse and among sexually experienced youth increasing the use of condoms and decreasing the number of sexual partners.  

### 6.3 Principles for reducing stigma in the family

The Regional consultation on stigma and HIV and AIDS, Dar-es-Salaam, Tanzania, June 2002 prioritized the following key responses to stigma within families and communities.

- Conduct research on disclosure and stigma in the family setting, and use the findings to design actions to promote openness and acceptance.
- Promote life skills education and counseling to help HIV-infected and affected children cope with stigma.
- Ensure that a package of services, including voluntary counseling and testing (VCT) and follow up care are available. This may be the most important consideration where stigma is concerned as it provides the family with hope. The community will be able to see a person diagnosed as positive receiving care and support. Often a situation exists whereby a person is diagnosed as positive and all in the community watch this person die with no support or hope of life, thus a package of services ensures hope and removes the sentence of quick death.
- Raise awareness so that families and communities can access interventions such as prevention of parent to child transmission, care and support services, as they become available, or hold authorities accountable if not available.
- Link families to active support service organisations and government safety nets.

Research conducted in Southern and Eastern Africa has identified the following needs among families caring for people with HIV and AIDS. Most families are compassionate and caring but stigma often makes the expression of this compassion difficult. The following guidelines can be used to support families

45 Ibid.
and reduce stigma in the home. Programs should involve all family members, particularly men, to encourage greater sharing of the burden of care within the household.  

- **Provide families with practical knowledge and skills for caring and counseling.** This, together with up to date, accurate information on HIV and AIDS can decrease stigma in homes by reducing fears of transmission in the course of providing care.
- **Help families recognize stigma in the household** so that they may be in a better position to provide care that is free of stigma, respectful, sensitive and more understanding of PLWHA.
- **Supplement and support limited financial and emotional resources.** A number of practical considerations such as poverty and lack of medical facilities, counseling and home based care can place the burden of care on women. These factors can contribute to caregivers the person living with HIV and AIDS. Thus providing such households with financial support and other necessary services such as emotional support for care givers will go a long way to reducing stigma in the family.

### 6.4 Useful Reading Material

- Stigma and Discrimination Research Update, Horizons. [www.popcouncil.org/horizons](http://www.popcouncil.org/horizons)