siyam'kela

measuring hiv/aids related stigma

TACKLING HIV/AIDS STIGMA:
Guidelines for faith based organisations




Siyam'kela

*Siyam'kela **[SI-YUH-MU-GE-LAR**] is an African word from the Nguni language. Translated it means "We Are Accepting" expressing a collective embracing, understanding and acceptance of a challenge at a particular time. The word has thus been interpreted as "Together We Stand" for this project.*

The Project has been designed to explore HIV-related stigma, an aspect of the HIV/AIDS epidemic, which is having a profoundly negative effect on the response to people living with, and or affected by HIV/AIDS. Within the context of the Project, Siyam'kela denotes a collective approach in working towards reducing HIV/AIDS related stigma and discrimination.

siyam'kela

Tackling HIV/AIDS stigma:
Guidelines for faith-based organisations

December 2003

A joint project of the:

- POLICY Project, South Africa;
- Centre for the Study of AIDS, University of Pretoria;
- United States Agency for International Development (USAID); and
- Chief Directorate: HIV, AIDS & TB, Department of Health

Researched by:

- Insideout Research

Supported by:

- Representatives from the *Siyam'kela* Reference Groups

Contents

1. Background

1.1 The Siyam'kela Project

The *Siyam'kela* Project is a joint endeavour of the POLICY Project, the Centre for the Study of AIDS at the University of Pretoria, the United States Agency for International Development (USAID), and the Chief Directorate: HIV, AIDS and TB, National Department of Health. *Siyam'kela* is an African word meaning 'we are accepting', expressing a collective embracing. The project has interpreted the word as 'together we stand', to symbolise unity in challenging HIV/AIDS stigma.

Stigma, 'a powerful and discrediting social label that radically changes the way individuals view themselves and are viewed as persons'[1], can be **felt** (internal stigma), leading to an unwillingness to seek help and access resources, or **enacted** (external stigma), leading to discrimination on the basis of HIV status or association with someone who is living with HIV/AIDS.

Because stigma has an impact on prevention and care it is important to address it directly. However stigma-mitigation practice has not been well informed by theory and research. An urgent need was identified for indicators of stigma that can be used to develop interventions and measure their success.

The *Siyam'kela* Project thus aims to pave the way for a stigma-mitigation process by developing **well-researched indicators** of HIV/AIDS stigma and discrimination. The project has focused on three key areas essential to South Africa's response to HIV/AIDS:

- faith-based organisations and communities as important sources of support to people living with HIV/AIDS (PLHAs)
- national government departments as workplaces committed to dealing with stigma through good policy and practice
- the relationship between PLHAs and the media as an example of how empowered individuals can impact positively on perceptions and attitudes towards HIV/AIDS.

A comprehensive literature review, two consultative workshops and the

[1] Canadian HIV/AIDS Legal Network. (1998). HIV/AIDS and Discrimination: A Discussion Paper. Ottawa, Canadian HIV/AIDS Legal Network and the Canadian AIDS Society.

establishment of reference groups in the focus areas of the project ensured that a diverse range of opinions and experiences were reflected. The use of an independent research organisation, Insideout, for the fieldwork, also brought in a fresh perspective.

The project consists of **six aspects**:

- **a** literature review **to provide a theoretical understanding of stigma**
- a qualitative exploration of **stigma experiences and perspectives** through focus-group discussions and key-informant interviews across South Africa
- the development of **indicators of internal and external stigma** through this fieldwork and in consultation with experts in the field
- **a media scan** to contextualise and locate the fieldwork in a particular time and place
- the documentation of **"promising practices"** which mitigate HIV/AIDS stigma
- the development of **guidelines** to assist those who wish to develop interventions to impact positively on HIV/AIDS stigma.

1.2 Accepting environments

It is very important to address HIV/AIDS stigma in order to improve the quality of the lives of people living with HIV/AIDS and to address prevention effectively.

> *"A humane, loving environment allows PLHAs to move from bitterness to acceptance to understanding."*
>
> Faith leader

Powerful metaphors related to HIV/AIDS reinforce stigma and create a **sense of otherness**. Othering occurs when blame and shame are assigned to people living with HIV/AIDS. This sets a moral tone that contributes towards people conceptualising PLHAs as different, and guides thinking toward a 'them' and 'us' division. When this division occurs, a person is less likely to identify with the other group, in this case PLHAs.

For example, metaphors that refer to HIV/AIDS as a plague – and PLHAs by association as the carriers – presents PLHAs in a dehumanising and alien light.

The consequence of othering is that certain groups may feel that they are immune to the risk of HIV infection. Stigma also influences how we respond to the HIV/AIDS epidemic. Instead of using resources and energy effectively to provide a

caring, compassionate response, PLHAs, people representing risk groups, or people affected by HIV/AIDS have become **targets for blame and punishment**. This has only heightened their vulnerability to HIV/AIDS and pushed them into a vicious cycle of stigmatisation and discrimination.

> *"Acceptance is the key to many doors. And acceptance is probably one of the keys to the stigma door too."*
>
> Male person living with HIV/AIDS

As part of the qualitative exploration of HIV/AIDS stigma, the *Siyam'kela* study collected many personal experiences of people living with HIV/AIDS who have started to **heal emotionally** because of supportive and non-stigmatising environments. PLHAs mentioned particularly the value of proper pre- and post-test HIV/AIDS counselling, the provision of factual information about HIV/AIDS, opportunistic diseases and counselling about disclosure. PLHAs highlighted the importance of acceptance by their families, faith groups, friends and colleagues in helping them to overcome the initial shock of discovering their status. Acceptance from others helped them to accept their status and to live positively. Where PLHAs have not been able to find such support, they have also been more likely to internalise societal stigma.

These guidelines highlight the **importance of such an accepting environment** – not only for the healing of PLHAs, but also for creating an environment that allows open discussion and disclosure. It also and reduces the sense that HIV/AIDS is someone else's problem.

1.3 Purpose of the guidelines

These guidelines were developed to provide **faith leaders, HIVAIDS committees, PLHAs in the faith community and opinion leaders within the faith-based sector** with practical and user-friendly recommendations on how to create an environment free of HIV/AIDS stigma. Additional guidelines for PLHAs and media, and the national government workplace sector, are also available. The guidelines are not exhaustive and should be read **in conjunction with other guideline documents** produced on HIV/AIDS and stigma within the three sectors (see the Appendix: *Useful resources*).

> *An opinion leader is a lay person belonging to a faith-based organisation, who has a deep level of understanding of issues related to HIV/AIDS. They have a strong influential voice about HIV/AIDS issues within the structure of their faith-based organisation.*

The **purpose** of these guidelines is:

- to share the findings of the *Siyam'kela* study in a user-friendly way
- to increase responsiveness amongst faith leaders and opinion leaders regarding the importance of creating accepting environments to reduce HIV/AIDS stigma
- to provide recommendations on how to develop an HIV/AIDS-supportive environment.

The *Siyam'kela* guidelines were developed in several **phases:**

- First, an analysis was conducted of the findings of 23 focus groups and 11 key informant interviews with an overall focus on enabling factors for stigma-mitigation, and the relationship between PLHAs and the media.
- Next, there was broad consultation with reference-group members and participants in a consultative workshop. All participants involved in these processes had a wealth of HIV/AIDS knowledge and experience. Participants were representatives of the three chosen sectors – the workplace sector, faith organisations, and PLHAs with media experience.
- Within the faith sector, nine focus groups were held – one in each of the provinces. Three focus-groups were conducted with each category of participants, namely faith leaders, faith community members and PLHAs who belong or previously belonged to a faith group. Participants were drawn from the Christian faith (including the Catholic, Anglican, Methodist, Uniting Presbyterian and Dutch Reformed churches) and the Islamic faith.

  Faith leaders selected the participants for the faith community focus-groups, while the PLHAs were invited through the National Association for People Living with HIV/AIDS (NAPWA). It should be noted that the Islamic faith was not consistently represented in all focus-groups, and that in some cases faith leaders were not ordained leaders but rather opinion leaders involved in HIV/AIDS programmes within the faith setting.
- Finally, a draft guideline document was developed, and the document was circulated amongst 7 selected key HIV/AIDS experts for comment. Their feedback is reflected in this final set of guidelines.

This document is divided into the following sections:

- policy
- leadership
- interventions
- partnership.

2. Findings for faith-based organisations

2.1 Policy

Findings

> *"He went to the dominee [minister] and disclosed his HIV status, who said that he thought that the council should be told. The news shocked them that they agreed to share it with their wives, who were so shocked that they just felt that they needed to share it with their friends, who were so shocked that they needed to talk about it at the tea party."*
>
> Faith leader

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 PLHAs 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.

> *"The other problem is that we have faith communities, especially those that preach a lot about salvation saying, 'we are saved therefore this disease cannot happen to us'."*

The **lack of confidentiality** was a concern raised by participants in the *Siyam'kela* research project, and needs to be addressed in order to create a safe and accepting environment for PLHAs.

Faith leaders 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.

Recommendations

a) Develop guidelines

There is a need to develop guidelines that will assist faith leaders, as well as faith community members, on how to appropriately deal with HIV/AIDS and related stigma. These guidelines should cover how to: maintain confidentiality of HIV status, manage disclosure and provide appropriate support to those that are infected and affected by HIV/AIDS. The guidelines should be developed in consultation with PLHAs.

b) Mainstream HIV/AIDS stigma and guideline policies

HIV/AIDS and stigma-mitigation standards should be mainstreamed. A destigmatising 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.

c) 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.

2.2 Leadership

Findings

There are several challenges facing faith leaders. Some focus-group participants felt 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 faith.

Recommendations

a) Provide ongoing capacity building of faith leaders in stigma mitigation

The skills of the leadership need to be built up in order to effectively create and share anti-stigma messages and take responsibility for the stigma-mitigation process. Training should include:

- theological and ethical reflection on HIV/AIDS
- sensitising faith and opinion leaders to HIV/AIDS stigma by focusing on how stigma develops and the consequences to PLHAs, the faith community, and society
- exploring faith leaders' attitudes and prejudices and how these feed to HIV/AIDS stigma.

b) Encourage leadership to take responsibility

It is strongly recommended that leadership take responsibility for HIV/AIDS stigma-mitigation. This would not only include **driving** the process but also **monitoring** the implementation of stigma-mitigation policies.

c) Foster leadership commitment and involvement

The active involvement of faith leaders is highly recommended in efforts to create a stigma-free environment and should include participation in stigma-mitigation 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.

d) Include PLHAs in positions of leadership

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.

2.3 Interventions

Findings

This study found that faith groups are most comfortable in providing material, social and medical assistance to PLHAs, since this is a traditional role taken up by faith organisations or NGOs funded by faith communities. Examples include providing home-based care and conducting support groups. Many faith-based organisations also provide HIV/AIDS awareness raising campaigns – either through door-to-door campaigns or at schools.

"…Some conservative religious figures think of this [HIV/AIDS] as a wonderful opportunity to bring the folk back onto the path of morality: 'See what is happening to people who do all these bad things?' So HIV/AIDS is an opportunistic disease for religious conservative people. A wonderful opportunity for us to warn our people... The only discourse is how do we rail against this immorality that is leading to it, and that is then disguised as prevention."

Faith opinion leader

The majority of the services offered by faith-based organisations have not been modified in response to the HIV/AIDS epidemic or to HIV/AIDS stigma. However, pre-marital counselling is one example where HIV/AIDS is now included as a core topic. HIV/AIDS is also included as a topic in sermons, but usually to preach about the consequences of 'immoral' behaviour.

Faith-based organisations continue to debate about what appropriate **HIV/AIDS prevention messages** are. Specifically, the question of whether or not to promote condom use along with messages regarding faithfulness and abstinence is still unanswered in some faith groups. Faith leaders sometimes present prevention messages in a non-accepting and punitive manner.

Recommendations

a) 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 as well as highlight **factors enhancing mitigation**. The assessment should refer to, and build on, the *Siyam'kela* HIV/AIDS stigma-indicators which will help measure stigma and monitor the impact of stigma-mitigation process. The assessment may include a survey with faith community – to learn more about their perceptions of PLHAs 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.

b) Involve PLHAs 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 PLHAs in addressing the pandemic and to act as HIV/AIDS advocates for positive living. PLHAs have unique experiences and expertise that should be used as a resource. PLHAs' experience and insights could be used in the:

- development of HIV/AIDS-related policies and programmes
- delivery of programmes
- monitoring and implementation of programmes.

By **involving PLHAs**, 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. PLHAs 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 PLHAs. Such role modeling will also begin to de-stigmatise the disease.

It is suggested that **PLHAs 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.

c) 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**.

d) Raise awareness in faith communities

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

e) Move beyond providing information only

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**. 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 classism. A skilled facilitator is necessary to run these sessions.

f) Mainstream stigma-mitigation messages

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

g) Use non-stereotypical images and concepts of PLHAs

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 PLHAs as frail and sickly or HIV/AIDS as affecting gay men only. Such images contribute to feelings of hopelessness and the perception that PLHAs 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 PLHAs as 'promiscuous' and 'immoral', and as a danger to members of the faith community
- images of PLHAs 'at death's door'
- images of PLHAs as unable to live fulfilling lives because of their HIV-positive status
- understanding of HIV/AIDS as a 'scourge' or plague
- understanding of some PLHAs as innocent, which implies that some PLHAs 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*.

h) 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.

2.4 Partnerships

Findings

Partnerships with other organisations are vital for effective response to the needs of PLHAs. This includes sharing resources and information.

Many faith-based organisations have initiated partnerships and network with other faith groups and non-governmental organisations working in the HIV/AIDS field. For example, some faith groups are working with hospices to provide training in home-based care or with the Department of Social Development to assist PLHAs in applying for social grants.

Recommendations

a) Identify strategic partnerships

Existing partnerships should be encouraged to extend their HIV/AIDS response to include HIV/AIDS stigma. **New partnerships** could also be explored to allow interventions to be more holistic and diverse. It is also recommended that a way be found to hold partners **accountable** to their commitment to the creation of a stigma-free faith environment.

b) **Make referrals to existing services**

Partnerships should also be explored with **existing service providers** who may be able to assist with support for PLHAs. These services include:

- voluntary counselling and testing (VCT)
- assistance with social grants
- stigma-mitigation interventions
- access to treatment
- home/community- based care.

Information about referrals is necessary since some faith community members may want to use services outside of their immediate faith environment.

Appendix: Useful resources

Publications

- Catholic AIDS Action. (2001). *Caring for Ourselves in Order to Care for Others, Handbook for Death and Dying*. Windhoek, Namibia.

  A practical guide for pastoral care of PLHAs who are dying.

- Church of the Province of Southern Africa HIV/AIDS Ministries. (2002). *From Boksburg to Canterbury: Steps to Putting HIV/AIDS on the Anglican Map.*

  The report of the all-Africa meeting focuses on a strategic plan for HIV/AIDS ministry, and six key areas of concern: leadership, care, prevention, counseling, pastoral care, and death and dying.

- Holden S. (2003). *AIDS on the Agenda. Adapting Development and Humanitarian Programmes to meet the challenges of HIV/AIDS.* ActionAid, Oxfam GB and Save the Children UK.

  Provides practical tips on how to integrate HIV/AIDS response to existing social , financial and occupational systems.

- POLICY Project. (2001). *Planning our Responses to HIV/AIDS: A Step-by-step Guide to HIV/AIDS Planning for the Anglican Community*.

  Provides a model for strategic planning adaptable to different faith communities.

- POLICY Project. (2003). *Siyam'kela Research Project – Examining HIV/AIDS stigma in South African Media: January-March 2003. A summary.*

  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.

- POLICY Project. (2003). *Siyam'kela Research Project – HIV/AIDS stigma indicators: A tool for measuring the progress of HIV/AIDS stigma-mitigation.*

  Proposes indicators for measuring internal and external HIV/AIDS stigma. Highlighting the indicator's relationship to existing stigma, suggesting methods for verification in different contexts and listing conditions for the use of indicators.

- POLICY Project. (2003). *Siyam'kela Research Project – A literature review.* South Africa.

Provides a theoretical understanding *of* the origin, and manifestation of HIV/AIDS stigma and highlights the challenge for a stigma-mitigation process.

- POLICY Project. (2004). *Siyam'kela Research Project – Promising practices of stigma mitigation efforts from across South Africa: Reflections from faith-based organisations, people living with HIV/AIDS who interact with media and HIV/AIDS managers in the workplace.*

  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.

- Whiteside, A. (2002). *AIDS Brief for Professionals: Religious Leaders.* Health Economics and HIV/AIDS Research Division (HEARD), University of Natal.

- World Council of Churches. (2001). *Facing AIDS: The Challenge, the Churches' Response: Study Document.* WCC Publications.

  Provides a theological, ethical and human rights approach to HIV/AIDS, as well as a practical outline of what faith organisations can do.

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.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.

- 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.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.za

  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.wcc-coe.org

  The World Council of Churches site provides useful details of the council's stand against stigmatisation of PLHAs, pastoral care to PLHAs, and educating churches about HIV/AIDS.

- http://www.who.int/health-topics

  The World Health Organisation site provides the most update-to-date statistics on HIV/AIDS, women's rights in the pandemic, drugs, care and various international initiatives.

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