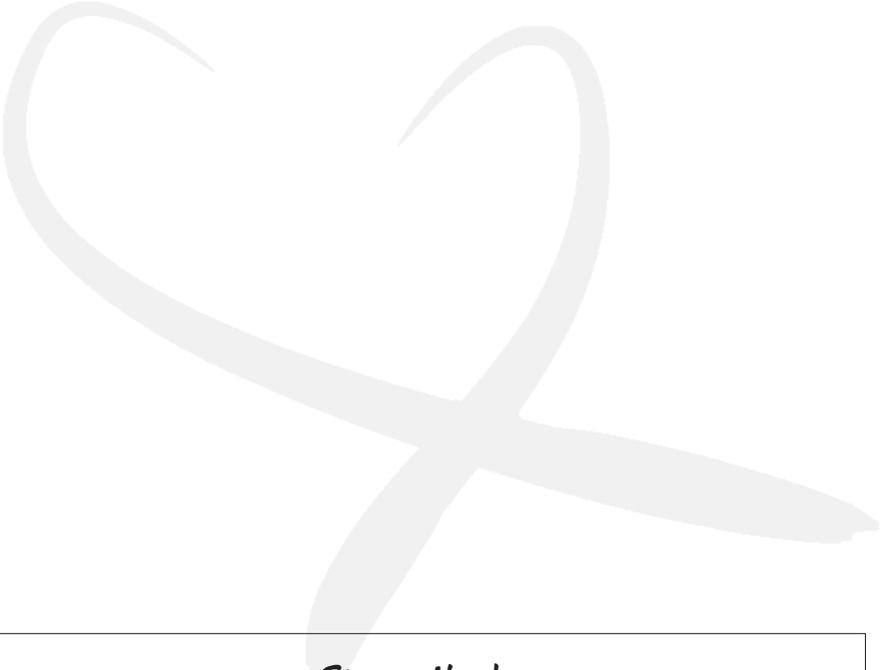


siyam'kela

measuring
related
hiv/aids
stigma

TACKLING HIV/AIDS STIGMA:
Guidelines for enhancing the interaction
of People Living with HIV/AIDS with the media





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.



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Tackling HIV/AIDS stigma: Guidelines for people living with HIV/AIDS who interact with the media

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

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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, which 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.

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.



A comprehensive literature review, two consultative workshops and the 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.

Powerful negative 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 – present 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, and 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.

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

“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

supportive and non-stigmatising environments. PLHAs mentioned particularly the value of proper pre- and post-test HIV counselling, the provision of factual information about the virus and opportunistic diseases, and counselling about disclosure. PLHAs highlighted the importance of acceptance by their family, faith group, friends and colleagues in helping them to overcome the initial shock of discovering their status. Acceptance also 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 reduces the sense that HIV/AIDS is somebody else's problem.

1.3 Purpose of the guidelines

These guidelines were developed to provide **leaders of PLHA organisations** with user-friendly recommendations on training for PLHAs, to strengthen their media advocacy roles in HIV/AIDS stigma-mitigation. Additional sets of guidelines are available for the faith and national government workplace sectors. The guidelines are not exhaustive and should be read in conjunction with other guideline documents on HIV/AIDS and stigma within the three sectors (see Appendix B: *Useful resources*).

The **purpose** of these guidelines is:

- to share the findings of the *Siyam'kela* research report in a user-friendly way
- to provide recommendations on training for PLHAs to strengthen their media advocacy roles in stigma mitigation.



The guideline was 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.
- The third phase drew on the experience of PLHAs who had interacted with the media. In total, nine focus groups were held – one in each province – and involving 59 participants. An effort was made to have gender-specific and race-specific groups, although this was not always possible. The participants were invited through the provincial offices of the National Association of People Living with HIV/AIDS (NAPWA).
- 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. *Interactions between PLHAs and the media*

2.1 *Findings*

According to the focus- group participants who were living with HIV/AIDS, **the media lack a sufficient number of empowered PLHA voices**. PLHAs felt that they should be **consulted** to assist with awareness

“If they hear it from the horse’s mouth, then they listen. It’s much better than to just read a story. I think that’s where the media can improve – they [television media] all have the opportunities to do that.”

Male person living with HIV/AIDS

messages and storylines for television and radio programmes. PLHA participants in the focus- groups believed that the media **perpetuate certain perceptions of**



HIV/AIDS and stereotype PLHAs.

Specifically, PLHAs were represented as sick and dying, 'promiscuous' and/or as only black women.

Some PLHA focus-group participants had had empowering interactions with the media, while others had had disempowering experiences. According to some PLHAs, media practitioners have selected only aspects of their stories in order to make their reports more newsworthy, or to make the story fit into their perspectives. Most PLHAs mentioned that they were asked inappropriate questions, such as:

- “Who infected you?”
- “Since when have you been positive?”
- “Have you been sleeping around?”
- “Does your partner know that you are HIV positive?”
- “How does it feel when you sleep with someone?”

“It is high time that our voices are heard. Let us not have other people telling us what they think should happen to a person who is living with HIV when we are here and know what it is like.”

Male person living with HIV/AIDS

“They actually only showed [my story] from the side they wanted to show. [The show] dealt with moral issues. The topic was whether [HIV] is a punishment from God or not. That was the direction they were going in and some of the things that they were saying, it seemed that they wanted people to believe that it is a punishment.”

Male person living with HIV/AIDS

2.2 Recommendations

a) Involve PLHAs in the media

One key recommendation is that **people living with HIV/AIDS should be involved in the media** to a greater extent. PLHAs have unique experiences and expertise, which could be used as a resource. By involving PLHAs, credibility can be given to HIV/AIDS programmes and reporting. PLHAs could also be effective spokespersons for stigma-mitigation.

The principle of the *Greater Involvement of People living with HIV/AIDS* commonly referred to as the **GIPA principle**, encourages organisations to involve PLHAs in addressing the pandemic and so enable PLHAs to act as HIV/AIDS advocates for positive living.



Specifically, PLHAs could be involved in the:

- development of guidelines for media practitioners
- development of television and radio programmes that are HIV/AIDS stigma-sensitive
- development of HIV/AIDS educational materials that are HIV/AIDS stigma-sensitive
- training of media workers on HIV/AIDS and stigma-related issues
- monitoring of the codes of conduct.

Although HIV/AIDS affects some groups disproportionately because of pre-existing social inequalities, recognition of this fact should not be at the cost of stigmatising such groups and creating the perception that HIV/AIDS only affects these groups, with others perceived as immune to the disease. The media may be able to show that HIV/AIDS affects us all by ensuring a broader representation of PLHAs in terms of demographics such as race, gender, age and geographic location.

b) Empower PLHAs to interact with the media in an assertive manner

In order for PLHAs to become more actively involved in media advocacy to reduce stigma, effort needs to be made to **build the capacity of PLHAs**. It is suggested that the training of PLHAs include:

- raising awareness of PLHAs' rights
- improving awareness of good practices for media interacting with PLHAs, including codes of conduct (see Appendix B: *Useful resources*)
- developing awareness of good media practices for representing PLHAs – this should include using empowering language and images
- enhancing awareness of possibilities for redress
- developing skills for good communication and for sustaining good relationships with the media
- developing skills in effective public disclosure of HIV status
- creating a supportive environment among PLHAs involved in working with the media
- improving skills for handling; leading questions, sensitive questions and difficult questions

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- sensitising to issues of stigma
- conscientising regarding the implications of working with the media.

Participating PLHAs gave this advice to PLHAs who intend to interact with the media:

- PLHAs need to first **come to terms with their HIV-positive status** and past experiences.
- PLHAs need to **be prepared for possible stigmatisation and discrimination**, which may also affect those related to or associated with the PLHA.
- PLHAs need to be prepared for **possible shock reactions of their family and friends** in response to public disclosure.
- PLHAs need to **be assertive** when interacting with media practitioners to ensure that their story is told in the way they intend it to be.

c) Advocate that media regulatory bodies accept ethical guidelines

PLHA organisations could play an active role in advocating for the integration into the existing **media ethics** in South Africa of the *Ethical Guidelines in Reporting on HIV and AIDS for South African Media* (2003), developed by the Centre for AIDS Development, Research and Evaluation (CADRE) (see Appendix B: *Useful resources*). PLHA organisations could approach editors and sub-editors, as well as the South African National Editors Forum (SANEF) and media regulatory bodies.

d) Produce HIV/AIDS stigma-mitigation messages

One way in which a PLHA organisation can mitigate stigma is through the **production of stigma-mitigating messages** using various forms of media – print, television and radio. Some positive examples of stigma-mitigation messages in the media include:

- *Soul City* – television, radio and print media campaigns are researched to ensure that the information and messages they broadcast are sensitive and correct.
- Bush Radio's daily *Positive Living* show, which is presented by a PLHA
- *Steps for the Future* (a range of short documentaries addressing HIV/AIDS which have been aired on television, in cinemas and are available on video)



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- *Beat It* and *Positive* – both television programmes with a stigma-mitigation message and presented by PLHAs
- *Living Openly* – a book highlighting the lives and experiences of People living with HIV/AIDS in South Africa, commissioned by the Beyond Awareness Campaign, National Department of Health.

e) **Address stigma with members of PLHA organisations**

PLHA organisations can target stigma directly by addressing the topic with members and running training courses on the topic. Knowledge of the nature and effects of stigma can enable members of PLHA organisations to effectively address the topic with others in their own capacity.



Appendix: Useful resources

Publications

- Centre for AIDS Development, Research and Evaluation (CADRE). (2003). *Ethical Guidelines in Reporting on HIV and AIDS for South African Media*.
Focuses on the rights of PLHAs, gender and HIV/AIDS, rights of infected and affected children, language, and rights and responsibilities of media practitioners, and implementation and monitoring.
- Change Project, Academic of Educational Development (AED) and the International Centre for Research on Women (ICRW). (2003). *Know Thyself – A Toolkit for Reducing Stigma that Could Work*.
- Gender Links and the AIDS Law Project. (2003). *Gender and HIV/AIDS – A Training Manual for Southern African Media and Communications*.
This training manual addresses the issues of communication, gender and HIV/AIDS, as well as the links between gender violence, culture, religion, and prevention and care in relation to HIV/AIDS.
- National Department of Health. (To be released April 2004). *To the Other Side of the Mountain: The faces and voices of people living with HIV and AIDS in South Africa*.
- 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.
- UNESCO. (2001). *Media and HIV/AIDS in East and Southern Africa: A Resource Book*.
Includes practical guidelines and strategies for effective reporting on HIV/AIDS issues.
- United Nations Development Programme. *Greater Involvement of People Living with HIV/AIDS (GIPA) Workplace Model*.
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.'
- Whiteside, A. (2002). *AIDS Brief for Sectoral Planners and Managers*. Health Economics and HIV/AIDS Research Division (HEARD) University of Natal.
This is one of a series of booklets funded by USAID, which aims to guide the

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media sector's response to HIV/AIDS. These booklets are available from HEARD – the Health Economics AIDS Research Division of the University of Natal.

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.

- <http://www.undp.org>

The website of the United Nations Development Programme outlines the Greater Involvement of People living with HIV/AIDS (GIPA) workplace model, and the unique contribution that PLHAs can make to workplace and other programmes. It provides contact details for organisations wishing to utilise the GIPA model.

- <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 PLHAs, including confidentiality, informed consent, responsibilities of media practitioners, how to interview PLHAs, and using language sensitively.

- <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.

- <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.

- <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.



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- <http://wwwserver.law.wits.ac.za/cals/OLPalp/>
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*.

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