

siyam'kela

measuring
related
hiv/aids
stigma

P r e l i m i n a r y I n d i c a t o r s
W o r k s h o p R e p o r t



...siyam'kela:
measuring HIV/AIDS
related stigma...



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:
measuring HIV/AIDS
related stigma...

siyam'kela

*Report of the first consultative workshop to develop
preliminary indicators of HIV/AIDS-related stigma*

27 - 28 November 2002

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

Supported by:

- Representatives from the Siyam'kela Reference Groups
- Insideout Research



1. Introduction

The POLICY Project has initiated a research project that aims to identify, inter alia, suitable indicators, which will enable organisations to measure the extent of, and the changes in HIV/AIDS-related stigma in local settings and institutions.

2. Purpose of the workshop

The purpose of the consultative workshop was to facilitate the development of useful draft indicators to measure the reduction in HIV/AIDS stigma within three focus areas: media, faith groups and national government. These draft indicators will be validated using field work and refined in a workshop to be held later.

3. Participants

A total of 17 participants attended the workshop. They represented the Centre for the Study of AIDS, the Policy Project, the four reference groups (national reference group, faith-based reference group, persons living with HIV/AIDS reference group, and national government departments reference group). Various other AIDS experts were also present. See Appendix I for the attendance list.

4. Overview of the process

Day one

- Welcome
- Presentations
- Small group work: development of objectives; discussion of manifestations of internal and external stigma
- Plenary session
- Small group work: development of indicators

Day two

- Plenary session: feedback
- Critical feedback from group and from facilitators
- Small group work: refinement of objectives and indicators
- Plenary session: feedback



5. Welcome and presentations

5.1 Welcome: Mary Crewe, Director, Centre for the Study of AIDS, (CSA)

Mary Crewe formally opened the workshop and welcomed the participants to the Centre. Mary shared some of her own insights about HIV-related stigma and expressed her support for the indicator development process.

5.2 Kevin Osborne: Presentation on global strategies to combat HIV/AIDS stigma and discrimination, and the Mexico Project

Kevin Osborne provided an overview of the project internationally and locally - and the rationale for it. In response to a question as to how and why the particular three sectors had been chosen, Kevin explained that the selection had been based on the need to provide a clear focus for the project. He added that it was not the intention of the study to address all aspect of stigmatisation. The three sectors were seen as representing institutions which people looked to for leadership, and were also institutions of power which shaped general perceptions.

A concern raised by the group was that working with national government departments might be experienced as restrictive, especially considering the time constraint of the project. A government representative commented that bureaucracy was often used as a means of slowing down or even stopping projects of this nature. It was argued that government was not sympathetic to the project, and some creative reflection was required regarding how to best approach those in government. Kevin acknowledged these obstacles and responded that the project could only attempt to do its best, and should at least document the constraints it encountered. See Appendix 2 for an outline of the presentation.

5.3 Caroline Wills: Presentation on measuring HIV/AIDS stigma in South Africa

Caroline Wills provided the group with a detailed account of the South African aspects of the project and its planned outcomes. Questions were asked about the development of indicators and whether separate indicators should be developed for each of the three sectors. It was agreed that there would be different indicators for each focus area, but that some indicators could be generic.

The assumption that work done at national level would naturally filter down to provincial and local levels was questioned. The view was expressed that the tension between the different tiers would make such sharing very difficult. It was concluded that the research would focus on national government departments, but that findings could then could be tested in other tiers.

Some people in the group felt that the indicators need not be gender specific, as this would mean that indicators would then also need to take into account other demographic characteristics, such as race.

A concern was raised that in the South African project there was a lack of focus on the gay community. Kevin responded by saying that indicators from both the Mexican and South African projects could be used as UNAIDS indicators of HIV/AIDS-related stigma. Care should be taken to not duplicate projects. Unlike the Mexican project, the South African study would be tackling indicator development for HIV/AIDS stigma mitigation from a generalized epidemic perspective. It was envisaged that the South African team could learn from and draw on the findings of the Mexican study.

The group asked for some clarification about the ultimate purpose of the project: was it to develop South African indicators or international indicators? Kevin emphasised that the main focus was on ownership of South African indicators. The project should concentrate on finding South African



indicators and not be too distracted by the possibility that some could also be used internationally. See Appendix 3 for an outline of the presentation.

5.4 Ndivhuwo Masindi: Literature review

Ndivhuwo Masindi presented an overview of the literature related to HIV/AIDS stigma, including how it is manifested in the family and community, in the workplace, and in relation to faith-based communities.

The group focused once again on gender issues. It was emphasised that 'gender sensitivity' should not be used to provide an unfair and skewed emphasis on the female experience, but should focus equally on the experiences of men. One person stated that in terms of the HIV/AIDS pandemic women tended to portray themselves as passive, while men were seen as the 'infectors' and were blamed for the pandemic. Such perceptions influenced the manner in which initiatives were implemented, and also how People Living with HIV/AIDS (PLHA) responded to stigma. The possibility that some stigma mitigation interventions could themselves be stigmatising was also raised.

The new name of the project was questioned as possibly being stigmatising in itself. Some argued that Siyam'kela, meaning we accept and we understand, sets up an 'us' and 'them' differential that the project should be attempting to break down. The issue was noted, but was left unresolved.

Social mobilisation was mentioned as an example of a strategy that had been successful in challenging norms and attitudes. Some African examples, including the Treatment Action Campaign (TAC), were mentioned. There was a sense, however, that no formal studies had yet been undertaken to measure the success of such initiatives.

A concern was raised that measuring stigma is a difficult task. It was stated that the research focus should be on descriptive behaviours rather than subjective accounts, since people affected by HIV/AIDS have been sensitised to provide 'politically correct' answers and would therefore not share their true feelings.

It was agreed that the research team would have to approach stigma questions in creative and indirect ways. For example, the example was given of a sex therapist who had asked doctors whether or not they treated HIV-positive patients with erectile dysfunction. Some doctors responded that they did not treat HIV-positive patients because such patients should not in any case be having sex. Had the doctors been asked directly whether or not they discriminated against PLHA, they would have answered that their behaviour was non-discriminatory.

The workshop group also discussed the importance of examining how policies in faith groups and government were contributing to stigma. For example, the content and language used in policies should be examined closely for possible stigmatisation.

The notion of 'AIDS orphans' was raised as a sensitive issue. An example was given: a poster had asked people to donate their 'bits of money' toward helping 'AIDS orphans' to get an 'appropriate' education. The poster statement highlighted the difference between so-called 'AIDS orphans' and other children, and could in fact contribute to their stigmatisation.

The difficulty in teasing out the various meanings of stigmatisation for PLHA was discussed. New and different manifestations of stigma appeared to be developing as the pandemic evolved. The issue was raised that other people might possibly feel resentment towards PLHA, and this phenomenon was attributed to the culture of entitlement amongst some PLHA, some of whom expected special and separate treatment. Learnt behaviours, such as the self-imposed exclusion of some from activities and situations due to internal stigma, would also have to be examined.



It was suggested that subtle forms of stigma needed to be looked at in detail. It was also suggested that although there has been some hesitation about learning from illnesses other than HIV/AIDS, they should be examined, to highlight the differences between various kinds of stigma for different illnesses and the reasons why they are different. A comment made by the group was that there are possible lessons that could be learnt from other 'vulnerable groups' who experience stigma, such as homosexuals, women and different races. We should learn from their attempts to challenge discrimination and address power relations. A copy of the literature review is available on www.csa.za.org.

5.5 Personal experiences of stigma

The three participating People Living with HIV/AIDS were asked to comment on stigma and, where possible, add some of their personal experiences of stigma. It was said that the meaning of sex and sexuality has changed for PLHA – they were seen by members of the community as wanting to deliberately infect others with the virus. Many PLHA have internalised this stigma and it inhibits their sexual expression. A person may abstain from sex, rather than expressing themselves freely sexually, despite their awareness that condoms reduce the risk of HIV transmission.

Other group members added that PLHA tended to create barriers around everything they do because of their HIV status, and because of their fear of infecting others: 'We lose our freedom of expression despite having a right to that expression, and despite both partners having to take on the responsibility. We block ourselves.'

It was observed that most AIDS educators would agree on a theoretical level that a condom could protect one from infection. However, if one of the sexually active partners is understood to be a PLHA then educators often question the effectiveness of condoms.

Regarding the workplace, the PLHA present commented that many human resources (HR) departments would not openly admit to discrimination because of a person's HIV status. There is a perception that faced with a choice between two otherwise equal candidates but with differing HIV status, HR departments would choose the HIV-negative candidate. A common argument of employers is that a company would not want to invest time and training in a person who is expected to only be productive and to stay with the company for a maximum of ten years. Such thinking, however, fails to take into account current research findings on the mobility of graduates, which has found that employees generally work for one company for an average of just three years before moving on to other companies.

One of the PLHA gave an example of how HIV-positive managers have to deal with a range of conflicts in companies because of their HIV status, although they are reluctant to admit to this because to complain is not considered to be 'politically correct'. This issue also raises the question of 'affirmative action for PLHA', which in itself may be stigmatising since such persons might be considered window dressing, rather than being valued for their skills.

Another example given of internalised stigma in the workplace is PLHA attempting to overcompensate for their HIV status in terms of performance. A PLHA stated that he worked much harder, worked longer hours and would not take time off work when he was sick because he felt that he would then be judged because of his HIV status.

Stigma was described as an 'underground' phenomenon which could fundamentally change the way an HIV-positive person lived their life.



6. Discussions and draft indicators

instruction

Each group were asked to:

The participants divided into groups to begin the process of developing baseline indicators. The groups focused on the three components of Siyam'kela, namely: Component 1, PLHA and the Media; Component 2, National Government Departments; and Component 3, Faith-Based Organisations.

Each group were asked to:

1. Brainstorm their own definition of internal and external stigma
2. Develop an objective of developing indicators for the component
3. Develop draft indicators

The response to these three instructions is outlined below including the response by the larger group.

6.1 Component 1: PLHA & the Media

6.1.1 Background

The media was seen as having played a powerful role over the last two decades in shaping the public's perception of HIV/AIDS. The media has generally represented HIV in a negative way and was described by the group as a 'manipulator of the truth', reporting on HIV/AIDS issues for its own interests. The media's focus is usually not on the 'average' story, but rather on sensationalist aspects. This has resulted in media images of HIV/AIDS which PLHA are unable to engage with. The media often portrays HIV/AIDS in terms of images of being a victim or of suffering, of hopelessness, of being an activist, or of PLHA being attacked or fighting. This results in a situation where there are no positive PLHA role models in the media with which PLHA can identify. The group concluded that such 'filtered' reporting is stigmatising.

The focus of the group's discussion was the need to promote positive, equal and 'real' representations of PLHA and the HIV/AIDS pandemic in the media. For this to happen, the group agreed that PLHA should be allowed to tell their own stories and to share their needs and issues in an appropriate manner. The media would have to report on and disseminate these stories in an accurate, positive manner. Some work has previously been undertaken with journalists to educate them on HIV/AIDS issues and to sensitise them to not use language that is stigmatising. It was therefore decided that the focus of this project would be on empowering PLHA.

6.1.2 Definition of stigma within the media

'The lack of a mutually respectful, constructive, engaging and equal relationship between PLHA and journalists, which has led to the misrepresentation, stigmatisation, and sensationalism of PLHA and their life stories.'



6.1.4 Objective

The objective was defined as empowering PLHA to constructively engage with the media, to ensure better representation and a more realistic and less stigmatising portrayal of their experiences.

6.1.5 Indicators

indicator	means of verification
<p><i>Role of media</i></p> <ul style="list-style-type: none"> ■ Use of non-stigmatising language and pictures to portray PLHA <ul style="list-style-type: none"> • words (<i>victim, suffer</i>) • themes (<i>pleasure, control, living, war</i>) • headlines • pictures • captions • placing ■ Extent to which PLHA are asked to comment on AIDS-related issues beyond personal testimony: <ul style="list-style-type: none"> • <i>policy issues</i> • <i>statistics</i> • <i>programmes</i> • <i>controversial issues</i> • <i>sexual health rights</i> • <i>human/legal rights</i> ■ Codes of conduct which address: <ul style="list-style-type: none"> • <i>stigma explicitly</i> • <i>relationships and PLHA</i> • <i>use of channels for redress</i> ■ Number of regular and dedicated spaces given for PLHA to report on ideas, opinions, etc. 	<ul style="list-style-type: none"> ■ Review and analysis of media ■ Media scan of who is interviewed and what they are asked about ■ Policy review (focused) ■ Media scan



indicator	means of verification
<p><i>PLHA perceptions and role</i></p> <ul style="list-style-type: none"> ■ PLHA perceptions of the relationship between them and the media ■ Willingness of PLHA to be interviewed by the media <ul style="list-style-type: none"> • <i>for the first time</i> • <i>after their first media experience</i> ■ PLHA proactively initiating and/or submitting a story to the media or being asked to do so ■ Degree of exposure or identification of PLHA in the media: <ul style="list-style-type: none"> • <i>not open / anonymous</i> • <i>partially open</i> • <i>completely open</i> ■ Where PLHA are represented: <ul style="list-style-type: none"> • <i>print</i> • <i>radio</i> • <i>TV</i> ■ PLHA engaging in empowered relationships with media: <ul style="list-style-type: none"> • <i>PLHA approving final story / text</i> • <i>Negotiating framework of story</i> • <i>Conscientised about implications of working with media</i> • <i>Skills in handling complex questions ('curved ball questions')</i> 	<ul style="list-style-type: none"> ■ Interviews ■ Interviews ■ Questionnaire ■ Focus groups ■ Review of PLHA stories and ascertaining who initiated the process, and what they were asked to comment on ■ Media scan over period of time ■ Interviews ■ Focus groups ■ Contracts ■ Correspondence ■ Commissioned piece? Fee paid? ■ Scale ■ Interview, focus groups ■ Review of PLHA interviews
<p><i>General/public perceptions</i></p> <ul style="list-style-type: none"> ■ Perceptions of which PLHA have their stories told most often told 	<ul style="list-style-type: none"> ■ Interviews
<p><i>PLHA reactions</i></p> <ul style="list-style-type: none"> ■ Reactions to post-media exposure (e.g. debriefing, fear, anxiety) 	<ul style="list-style-type: none"> ■ Scales
<p><i>Gender bias</i></p> <ul style="list-style-type: none"> ■ Extent of gender bias in the relationship between PLHA and the media, e.g. number of women compared to men who feel more/less empowered to tell their stories 	<ul style="list-style-type: none"> ■ Media scan



6.2.3 Indicators

indicator	means of verification
<ul style="list-style-type: none"> ■ Number of people living with HIV who have disclosed their status to the HIV/AIDS co-ordinator ■ Feelings, perceptions and experiences of stigma by PLHA within the workplace <ul style="list-style-type: none"> • male/female • GIPA /non-GIPA (<i>Greater Involvement of People Living with HIV/AIDS</i>) ■ Reactions to disclosure by management and other staff ■ Number of people accessing HIV/AIDS support provided by the employer. Support provided includes support groups, nutritional supplements (only by the Department of Mineral and Energy), immune boosters and counselling. ■ Number of reported cases of HIV-related stigma and discrimination reported to HIV/AIDS co-ordinators / unions / labour relations unit ■ How were these cases dealt with? ■ Number, nature, and update of HIV-related services provided by the workplace for all staff ■ Number of references addressing HIV/AIDS within government workplace policies ■ Degree of mainstreaming of HIV/AIDS in government departments <ul style="list-style-type: none"> • <i>Number and level of dedicated HIV/AIDS personnel</i> • <i>Existence and level of activity of AIDS working committee</i> • <i>Availability of HIV/AIDS budget</i> • <i>Number and nature of HIV/AIDS strategic plans</i> • <i>Existence of specific departmental policy</i> ■ Number of people who would disclose if tested HIV positive and the reason for their decision (warning: this could be measuring empathy) 	<ul style="list-style-type: none"> ■ Commitment records ■ Interviews/survey ■ Focus groups ■ Records from AIDS programme ■ Records from HIV co-ordinators/unions / labour relations unit ■ Survey, focus groups, key informer interviews ■ In-depth interview with HIV/AIDS co-ordinators ■ Literature review ■ Records from AIDS co-ordinators, senior management services: Directors, Chief Directors, Directors General ■ Questionnaire, survey



6.2.4 Concerns raised

The following concerns were raised by the group:

- Debate was needed regarding the need to define which workplace policies would be analysed.
- There was a need to analyse the number of policies related to HIV/AIDS, but also to unpack the references to stigma and human rights, and discrimination contained in these policies. There was also a need to analyse how policy deals with stigma and what the consequences of stigmatising are.
- There was a need to include the extra dimension of GIPA: what are people's responses to GIPA placements?
- There are areas which policy does not touch, such as entry into work sports teams and office gossip which are, however, also important to consider.
- What about intangible issues, such as the impact of a supportive manager and the attitudes of officials?

The question was raised whether the project would be looking at stigma in the workplace or at policies. The response was that it would be looking at both. The issue was also raised that policies are often 'nice ideas', but they require programmes to put them into action. We should therefore look at specific programmes. However, it was argued that policies are good starting points.

The legal environment determines many aspects of stigma – “the do's and don'ts” - and a department must introduce measures to reduce stigma. It would be interesting to see what programmes have resulted from the policies and how they have impacted on creating HIV/AIDS friendly and unfriendly environments. Would a person want to disclose in this environment? Would a person want to use the services? It would be important to measure employees' perceptions of illness in general, and HIV/AIDS specifically, to test whether the work environment was unsupportive and hostile toward all illnesses or just in relation to HIV/AIDS. Not all policies will produce positive results. Some departments will introduce measures, while others will not and some measures may be stigmatising themselves. A question was raised as to whether the objective should focus on 'examining' rather than 'improving'. It was agreed that this study would focus on obtaining baseline information on what the current situation is at the workplace. The information would then be used to develop appropriate interventions.

The question of confidentiality was raised in relation to obtaining records which reflect who has disclosed their status. There was also uncertainty about whether government would share these records. It was suggested that we use small focus groups to ask people about their perceptions regarding what is happening in their departments in relation to HIV.



6.3 Faith-based organisations

6.3.1 Definition of stigma within the faith-based environment

A set of ideas (myths, beliefs, scripture, social context, ideas of the world) which lead faith-based organisations to act / not act in certain ways which exclude, judge, patronise, condemn, and label PLHA (and significant people in their lives), producing a set of responses in PLHA (and their significant others).'

6.3.2 Objective

The objective was defined as reducing overt acts of discrimination and stigma against PLHA (and their significant others) in order to create an HIV-friendly space for PLHA (and their significant others) in faith-based contexts.

HIV-friendly was conceptualised to include all aspects of religious life, including the content of the sermons, services provided, and the general level of comfort experienced by PLHA. This could be assessed by answering the following questions:

- Is HIV mentioned in prayer or preaching in a regular non-stigmatising way?
- Are PLHA used as a resource?
- Is voluntary counselling and testing offered or are people directed to such services?
- Would people be able to talk about their HIV status in a caring, supportive structure?
- Is a positive atmosphere experienced by 'followers' and is there privacy about disclosure?
- Are HIV-dedicated services provided and made available to people?

Overt acts of discrimination and stigma included the following acts directed at PLHA:

- Exclusion from religious practices
- Rejection
- Shunning
- Condemnation from the pulpit
- Exclusion from leadership positions
- Failure to act (church not providing services to PLHA)



6.3.3 Indicators

indicators	means of verification
<p><i>Attempts by faith-based organisations to come to terms with HIV/AIDS</i></p> <ul style="list-style-type: none"> ■ Training/information sessions <ul style="list-style-type: none"> • Number of training sessions on HIV/AIDS (prevention, care and reflection on the doctrinal aspects of ordained leaders, opinion leaders, and future leaders) • Extent to which discriminatory and stigmatising language is used in training materials and courses (content and quality) • Extent to which information is made available to congregants • Quality of information shared with congregants: non-discriminatory and non-stigmatising ■ Public statements and policies (prevailing attitudes about HIV within faith-based contexts): <ul style="list-style-type: none"> ■ Level of openness about sexuality: <ul style="list-style-type: none"> • Extent to which congregants feel comfortable to speak openly about sex within their religious setting • Leaders and opinion leaders speaking about condoms in a positive way (vs. providing misinformation) ■ Nature and frequency of public (formal delivery) messages, types of messages (e.g. AIDS is a punishment) ■ Nature and frequency of 'non-public' (overheard, incidental) messages ■ Existence of a policy on HIV/AIDS ■ Extent to which this policy is known by followers ■ Extent to which followers disclose their HIV status within the faith-based groups (publicly and privately to leader) ■ Knowledge of someone living with HIV/AIDS in the faith-based group (including leaders) ■ Acceptance of HIV -positive leaders (continued service, promotion, continued training) 	<ul style="list-style-type: none"> ■ 'Representative' case studies: across religions, geographical area, class, race. Including leaders, opinion leaders, followers – but most importantly PLHA ■ Interviews, focus groups ■ Content analysis of training materials ■ Literature review of existing HIV/AIDS related policies, guidelines and 'sacred utterances' ■ Interviews, focus groups, survey



6.3.4 Debate

The literature review was seen as providing the study with an ideal of what faith groups have set out to do against which their performance could be measured.

A concern was raised that faith groups do not keep accurate records – especially on HIV/AIDS – and that records should not provide the main form of verification. The indicators should also focus on access to services. The issue was raised that it was not a necessarily reasonable to assume that churches see their primary role as service provision. In South Africa, it was argued, the churches lost their service aspect during the apartheid years. It was, however, agreed, that services provided include funerals, marriages and counselling, and that these services could be used by the faith groups to talk about HIV. One participant stated that the AIDS pandemic is forcing the church to re-examine the aspect of provision of services.

There was also a concern expressed that the study of faith-based groups could be too broad and that there may be a need to focus on certain religious groups only. The research team would try to cover all major religious groups according to province. It was also acknowledged that the group did not have enough knowledge of the different faith-based groups to develop extensive indicators – for example, the definition of services provided by different faith-based groups needs to be explored. Some of these services would, however, be generic, for example, induction and acceptance processes. It was decided that the focus should be on PLHA and that participants could be identified through a snowballing technique.

7. Evaluation of the process

According to the feedback given by the participants, the two-day workshop met everyone's expectations. However, some participants felt that this was only the beginning of the process and they regretted that the way forward was not discussed. Participants felt that they had achieved adequate consensus and that the workshop provided them with sufficient discussion regarding the definition of stigma. The group also believed that they had worked hard and managed to come up with good indicators.

8. Way forward

The next stage of the process is the validation of the indicators for each of the three sectors. This will include the conducting of 24 focus groups, a media scan and 30 key informant interviews. The fieldwork will aim to collect themes of stigma (internal and external) and compare them to the developed draft indicators. This stage should be completed by the end of March 2003 and feedback will then be given to the four reference groups.

9. Conclusion

Thanks were extended to the participants and organisers of the workshop for their commitment, time and dedication to making the workshop a success.



Appendix 1: Attendance list

Apologies

Dr Nono Simelela (Department of Health), Busi Chamane (GIPA) and Angie Diale (PLHA reference group) sent their apologies. Angie Diale did, however, attend the workshop for a few hours on the second day.

Present

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Stigma and Discrimination Core Package: Mexico and South Africa

Kevin Osborne
POLICY Project



Agenda

- *Core Package Introduction*
- *Rationale*
- *Key Objectives*
- *Framework*
- *Methodology*
- *Expected Outcomes/ Results*



POLICY Core Packages

- Push the global policy agenda
- Linked to country program
- Time limited
- Results focused
- Ownership of package by country stakeholders



Rationale

- Answer global concern and increased rhetoric
- Need to demonstrate how HIV/AIDS-related stigma and discrimination can be reduced through careful analysis and replicable interventions
- Strengthen and expand UNAIDS global stigma and discrimination indicators
- Understand internal ('felt') stigma and external ('enacted') stigma

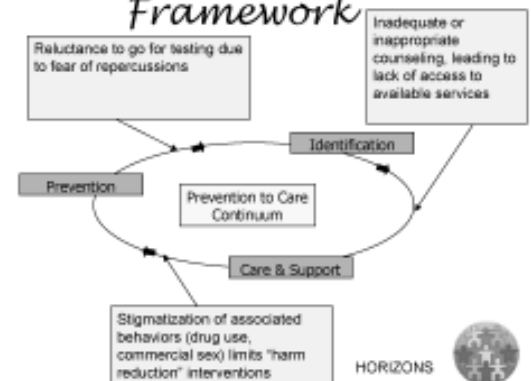


Key Objectives

- To empower those affected by HIV/AIDS stigma to act on the link between policy; individual actions and community support
- To document individual and community lessons where stigma has been successfully addressed
- To proactively link stigma to future programming and policy issues- at national, regional, and global levels
- Process is part of the product



Framework

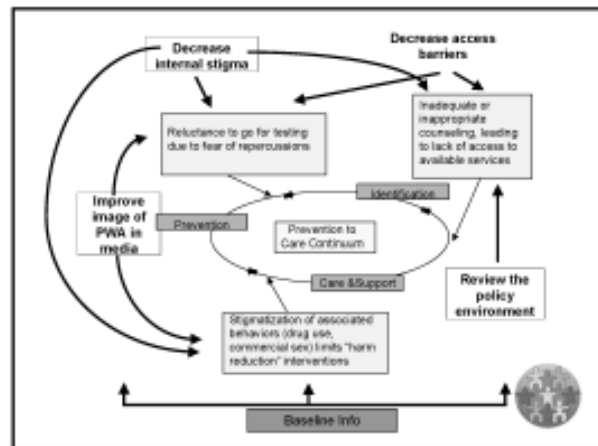




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Methodology

- What?
 - Level one: Individual impacts
 - Level two: Access to and use of available services
 - Level three: Policy and human rights environment
 - Level four: Media
- Who?
 - Empowering organizations of PWAS
 - MSM
 - Generalized epidemic women
- How?
 - Operational research on stigma and discrimination
 - Research and program interventions
 - Documentation



Expected Outcomes/ Results

- Expanded indicators for use by program managers, donor agencies etc.
- Program opportunities to address stigma and discrimination
- A comprehensive analysis of AIDS stigma in Mexico and South Africa
- Community and people focused lessons on addressing stigma and discrimination



Expected Outcomes/ Results continued


- Evidence of the impact of HIV/AIDS legislation and policy on issues related to stigma and discrimination
- Increased involvement of PWAs
- Programmatic implications for implementation at the national level to address issues related to both care and prevention
- Increased collaboration between PWAs, policy-makers, and civil society





Siyam'kela
Research project on HIV/AIDS related stigma
and discrimination

The POLICY Project
Center for the Study of AIDS,
University of Pretoria
In collaboration with
•National Department of Health
•USAID



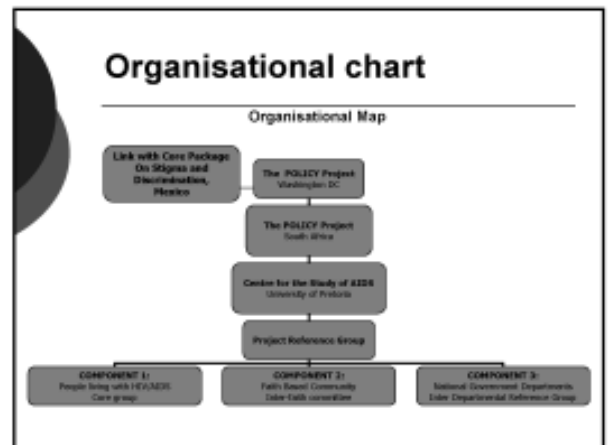
Background photos courtesy of Gideon Mendel's book entitled "Broken Landscape"

Aim of the research

- Develop suitable indicators which will enable us to measure the impact of stigma and discrimination in the future.
- To identify, review and document best practice interventions which we believe have or are currently reducing HIV related stigma and discrimination.

The project will support:

- The UNAIDS priority theme for 2002/3
- UNGASS
- Build on existing SA research



Process

South Africa	Mexico
• Generalised epidemic	• Concentrated epidemic
<p>Similar core areas</p> <ul style="list-style-type: none"> • Baseline developed • Process is product 	

3 components

- People living with HIV/AIDS
- Faith based community
- HIV/AIDS and the workplace



Process of research

- Establishment of reference groups
- Literature review
- Develop baseline indicators of internal and external stigma
- Conduct media scan
- Verify the indicators through field work
- Identify "best practice" interventions
- Develop interventions to mitigate the impact of stigma

People Living with HIV/AIDS (PWAs):

- Work with PWA organisations and engage in a skills building process
- Focus on:
 - The implications of disclosure
 - How public perceptions of PWAs are influenced by media and how this can be improved
 - How PWAs can engage pro-actively with the press to reduce HIV related stigma and discrimination

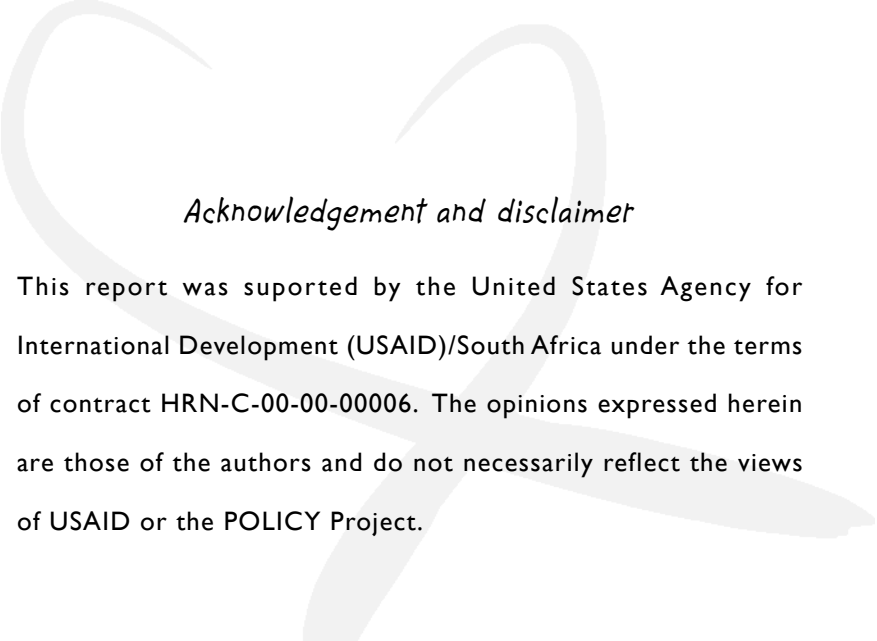
Faith based organisations

- Work with FB leaders to assist them to
 - Better understand stigma and the adverse affects stigma has on the availability and accessibility of services
 - Embrace PWAs
 - Transform their faith services to accommodate PWAs
 - Guide their local faith community to consider how important it is to reduce stigma and discrimination

National government depts.

- Explore whether the adoption of HIV/AIDS workplace policies and programmes creates a conducive environment for disclosure
- Create a set of guidelines on best practice in the workplace

"Very few companies have developed strategies to combat fear, stigma and discrimination in the workplace..... and this makes employment settings one of the key contexts in which responses aimed at reducing stigmatization must be implemented"



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