Regional Consultation Report

Stigma and HIV/AIDS in Africa: Setting the Operational Research Agenda

4 - 6 June 2001
Dar-es-Salaam
Tanzania

UNAIDS Intercountry Team for East and Southern Africa
Health & Development Networks (HDN)
Swedish International Development Agency (SIDA)

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INTRODUCTION

This report provides an account of the deliberations that took place during the regional consultation meeting Stigma and HIV/AIDS in Africa: Setting the Operational Research Agenda, that took place in Dar-es-Salaam, Tanzania from 4-6 June 2001. It was attended by 80 participants representing organisations of people living with HIV/AIDS, physicians, nurses, researchers, communications specialists, community workers, faith-based organisations and UN agencies from 15 countries, primarily from Eastern and Southern Africa.

The overall aim of the consultation was to identify concrete operational research priorities in order to better understand and address HIV/AIDS-related stigma.

The specific objectives of this consultation were to:

- Discuss and prioritise an operational research agenda for HIV/AIDS-related stigma.
- Identify potential partners, both technical and financial, to conduct research and utilise findings.
- Form a technical working group on stigma and HIV/AIDS to guide the research agenda.

The consultation was part of a project between UNAIDS Intercountry Team for East and Southern Africa and HDN with financial support from SIDA. The overall aim of the project was to facilitate the development of an operational research agenda on stigma and HIV/AIDS in Africa, by using a variety of participatory methods to solicit input. These methods included:

- A structured and moderated debate using a specialised e-mail discussion forum "Stigma-AIDS" which engaged over 1200 people from around the region. A formal evaluation of this time-limited forum was also carried out.

- Focus group discussions and key informant interviews with health care providers, including doctors, nurses, counsellors and traditional healers, people living with HIV/AIDS (PLHAs), the media and religious leaders and organisations. These were conducted in Botswana, South Africa and Tanzania using a questionnaire designed to explore stigma.

- A regional consultation meeting to consolidate input so far and develop the operational research agenda.

The meeting background documents, presentations and background information are available via the world wide web at: http://www.hdnet.org An index of each of the documents available through the website is provided in Annex 1.

MEETING OUTCOMES

Working definition on stigma and HIV/AIDS in Africa

This working definition of HIV/AIDS-related stigma took into account views expressed via the Stigma-AIDS e-mail discussion forum and the focus group discussions. It was produced by the working group on definition and context during the consultation meeting:

"HIV/AIDS-related stigma is a real or perceived negative response to a person or persons by individuals, communities or society. It is characterized by rejection, denial, discrediting, disregarding, underrating and social distance. It frequently leads to discrimination and violation of human rights".

Operational Research Agenda for Stigma and HIV/AIDS in Africa

The following operational research agenda, in the form of research questions and ideas for research and action, has been compiled based on the knowledge and experience presented from the following sources:

- Stigma-AIDS e-mail discussion forum
- Literature review
- Focus group discussions and key informant interviews
- Consultation meeting in Tanzania

The agenda has been divided into six main categories to help focus on the various operational research gaps that need to be highlighted:

- Definition and context
- Health care sector
- People living with HIV/AIDS
- Religious sector
- Communication
- Indicators to measure stigma

Stigma: definition and context

- What factors work best in reducing HIV/AIDS-related stigma as it affects children?
- What culturally acceptable approaches can be used successfully to reduce stigma?
- What factors have enabled some communities to overcome and move beyond stigmatising responses to HIV/AIDS?
- How do individuals move beyond stigma to face the possibility of having HIV within the current environment? What personal factors enable these people to seek testing, and what enables those who test positive to deal openly with their status?
- What forms does HIV/AIDS-related stigma take across different East and Southern African cultural groups, communities and countries?
- What are the common characteristics of HIV/AIDS-related stigma in East and Southern Africa?
- What are the determinants of HIV/AIDS-related stigma in different contexts?
- What 'best practice' models of stigma reduction are there that can influence interventions and programs.
- How do we understand better the relationship between stigma, discrimination and human rights in specific settings?

- What are the power relations that surround stigma? In particular, we must address the question of who defines stigma – is it the stigmatized individual, or is it those observing the stigmatization process and participating in it?
- What have been the most effective educational campaigns to reduce stigma on a societal level?
- How have countries actually modified the political culture to produce the supportive environment and to actualize pro-HIV policies that help reduce stigma?
- What is the damage done to those experiencing stigma?

Stigma and the health care sector

- To what extent is stigma present amongst health care providers (HCP)?
- What are the determinants of stigma among HCP?
- Does access to specialized provision of care and support reduce stigma?
- Does development of links between clinical and community-based facilities reduce stigma?
- What is the impact of stigma on voluntary counselling and testing (VCT): uptake, quality of counselling and outcomes?
- What is the impact of VCT on stigma? Does it increase stigma or help to reduce it?
- Assess longitudinally people who access VCT over period of time. Start before pre-test to see whether people are self stigmatizing and/or experience stigma from outside.
- Assess to what extent the surrounding environment perpetuates stigmatisation within VCT settings and how we can intervene.

Ideas for Intervention

- In the intermediate and long term, design a practical guide for in-service orientation and sensitization tool and build motivation and awareness among health care providers to recognize and avoid stigmatizing behaviors.
- Conduct intervention linked research to better understand the potential impact of antiretrovirals on reducing stigma.
- At the client, care provider and hospital management levels, promote disclosure of results to significant others while protecting confidentiality.
- Assess the PLHA-friendliness of services.

Stigma and people living with HIV/AIDS

- Do all HIV-positive people experience self-stigmatisation? If not, how do people avoid this vicious cycle?
- What can be done to help people move more quickly through the stages of realization and toward full and productive lives as positive people?
- What are the effects of HIV-related stigma, including self-stigma, on the productivity of an HIV-positive individual?
- Is perceived stigma worse than actual stigma and do both require different approaches in terms of understanding, research and interventions?
- To what degree is disclosure an effective tool in HIV prevention? Do public testimonials of HIV-positive individuals influence sustained reductions in risk behaviours among the uninfected?
- What are the reasons that HIV-positive people go public with their positive status?
- Do people experience different levels of stigma when they are healthy and living with HIV and when they are sick with AIDS?
- What is the relationship between stigma and secrecy vs. shared confidentiality?

- What is the relationship between the greater involvement of people living with HIV/AIDS (GIPA) strategy, support groups, PLHA associations and stigma?
- What is the relationship between stigma and risk perception?
- What is the link between provision of effective care/treatment/nutrition and stigma or stigma reduction?
- What impact does stigma have on the quality of life for children and youth (Adapt the WHOQOL standard psychometric tool)?
- What is the impact of stigma on behaviour change.

Ideas for Intervention

- A checklist to assess the level of stigma. This should be a diagnostic tool that can assess the level of stigma within a family/community which will be useful in counselling, disclosure, community organisation, advocacy, etc. Checklist could be used to read the situation at national, community, or family levels.
- A strategic approach to disclosure that prepares people for how, when and where they should disclose.
- National policies for essential package of care, where each player has clearly defined roles, government, NGOs, PLHA organizations etc. Governments should provide the policy framework and coordination.
- Longitudinal programme impact research on psychosocial support initiatives for children
- Youth and child participation in programming.
- Effectiveness and impact of life skills education to cope with stigma.

Stigma and the religious sector

- What are indicators for stigma within a religious group, and what makes these indicators unique to the religious group?
- What are the differences in stigmatization between religions?
- Do we have examples of religious groups where stigma is minimal or has substantially decreased over the past two years?
- What is the relationship between strict moral teaching and stigma?
- Within the local community experience, how can personal faith be explored, respected, and affirmed as a fundamental strength for community response and destigmatization?
- What are the characteristics of an integrated care and prevention approach that allows for conflict resolution and results in stigma reduction?
- Regarding partnerships of the religious sector with other non-sectarian agencies, how can theological principles and identity be expressed respectfully, and linked to practices that are encouraged by the partners (such as counselling, behaviour change interventions, harm reduction, family protection, etc.)?
- What evidence exists that organizational response can be accelerated by community participation approaches that involve people, including leaders, from the religious sector?
- Can we compare levels of stigma in different communities by having one community where religious leaders talk openly, for example, about condoms and another where they do not?
- What is the impact of accumulating loss in families and communities? How does faith and future hope interrelate with the accumulating loss?
- How can capacity for shared confidentiality within groups be linked to scaling up both care and prevention action and impact?
- What is the level of knowledge, attitude and practices of religious leaders about HIV/AIDS?

- In what ways do religious leaders stigmatise and discriminate as perceived by communities?
- In what ways do members of the congregation (community) stigmatise and discriminate against individuals and families affected by HIV/AIDS?
- How are shame, guilt and isolation fueled by religious teachings and values?
- To what extent do religious values and teaching help to reduce stigma?
- How can religious leaders and groups be influenced to give accurate information to members of their communities?
- What is the relationship between stigma and gender inequalities within religious groups

Stigma and communication

- How does the media perpetuate stigma?
- What types of media messages and images perpetuate stigma?
- What types of media messages and images reduce stigma?
- What role do mass media have to play in the AIDS information, communication and education challenge, with special focus on stigma?
- Is the media considered a credible source of HIV/AIDS information in African countries? How can the role of the media be strengthened to improve the credibility?
- What type of communication is the most appropriate?
- What media is effective in reducing stigma?
- How can the infected and affected people be involved in the information and communication process to influence the desired change?
- What is the effectiveness of sensitisation programmes for media people aimed at better HIV news coverage?
- What are the issues of stigma and denial within media ranks?
- How much influence does the commercial element have in constraining the mass media from fulfilling their social obligation to inform and challenge AIDS stigma?
- How do HIV/AIDS project planners value the mass media as an integral part of the overall communication process, and what strategic links have been established? Who is appropriately positioned to communicate about stigma in various settings?
- When is it appropriate to deliver the message?
- How does personal communication contribute to/decrease stigma?
- Which language is appropriate and not appropriate for use? How do we use stigma?
- To deliver effective messages we must first work out who are the prime target audiences, by sex, age, gender, educational background, values, perceptions, beliefs, lifestyles, sexual behaviour.

Indicators to measure stigma

- Identify indicators for global dimensions of stigma and methods for illiciting local dimensions of stigma.
- Methods to understand underlying causes of stigma in Africa need to be explored and disseminated.
- Methods that look at issues around disclosure and stigma in a family setting need to be explored (including checking longitudinal data).
- Example of specific indicators:
  - How many men and women go for testing as an indicator?
  - How many men and women are open about their status?

- Percentage of AIDS funerals attended by at least 75% of the village population divided by the percentage of AIDS funerals (Care International)
- Percentage of people in a community going for VCT
- Percentage of people testing positive and disclosing status to various categories of people
- Percentage of people using AIDS hotline services
- Percentage of positive people joining support groups (by sex)
- Percentage of people with HIV who report they delay seeking care
- Percentage of people who seek care located far away
- Percentage of people who report self segregation of personal items

Gaps in existing tools for measuring stigma:

- Questions on different dimensions of stigma and denial, such as willingness to disclose, social isolation, or enacted stigma.
- Guidelines for qualitative explorations of stigma, denial and discrimination that could facilitate the development of locally relevant indicators, within globally relevant dimensions.
- Validation and adaptation of existing tools in new settings.
- Tools for assessing stigma, denial, and discrimination in new settings that include not only different cultures, but different institutions (e.g. workplaces, hospitals).
- Questionnaire items on actual, as opposed to hypothetical, incidents. For instance, questions that can be posed to family care givers, health care workers.
- Questionnaire items that address stigma directed towards people who are not necessarily HIV positive, but who are associated with HIV/AIDS or with PLWA, such as health care workers, sex workers, injecting drug users, providers of home-based care, and family members.
- Tools to capture stigmatizing representations of PLHA in media, public health communications, and in government policy.

Main themes emerging from the conference

Throughout the consultation, a number of important themes emerged from the presentations, discussion and working groups:

- **Family**. Stigma in the realm of the family is one most subtle and debilitating forms of stigma and also the hardest to address. Special efforts need to be made to reduce the stigma at this level by working through interventions, such as home-based care programmes.
- **Children**. Children should not be subsumed under “everyone’ as they face different challenges with regards to stigma. We need to involve children as active partners in research and interventions, rather than as passive recipients.
- **Community involvement** is needed at all stages. It was repeatedly stated that we need to make communities active participants rather than passive recipients. There is a need to move away from experts from outside coming in an imposing research and interventions and to harness the power of communities. The role of NGO and government is to facilitate and support that community initiative and management.
- **People living with HIV/AIDS (PLHA’s)**. A continuing theme was that PLHA’s need to be much more involved at all stages.
  - PLHA’s are a resource and have much to offer, but many of the PLHA’s who have come forward are from the lower socio-economic strata. They are poor, poorly educated, and do not have much influence over the more influential (powerful)

segments of society. Those with skills, education, power & influence - professionals - are not coming out in the open, so are not able to tap their resources as PLHA's.
  - Support and development for professional PLHA's to become more actively involved to offer their skills and become advocates.
  - Commitment to train, improve the capacity of PLHA's to have the skills to be full participants in research and NGOs.
  - **Research and interventions.** Tension between the urgency to move on with interventions to address stigma versus the need to do operational research. In most contexts stigma is a very poorly defined and poorly understood concept---we do not have a strong understanding of the underlying roots and causes. Research should be action oriented research (operations research). There is a need to gather what we already know about stigma and interventions that have successfully addressed it and use that as a foundation.

Morality. There was a call for more open discussion of sexuality and sex as a way of destigmatizing HIV/AIDS. Part of the stigma is that AIDS is equated with immorality---- there is a need to separate AIDS and morality.

- **Faith-based organisations.** Faith-based groups are key players in both creating/perpetuating stigma, but also in breaking it down. Very important to get faith-based groups involved and to find common ground between the secular and faith communities.
  - Personal faith is very important and a resource for care, change and hope.
  - As represented by individuals and families, local faith-based institutions are a strength for change, for example they could be harnessed in an attempt to promote shared confidentiality.
- **Partnerships.** Partnerships on many levels are required; there is a need to change the status quo of what exists now so that communities, faith-based groups, families and PLHA's are the main **actors** and decision-makers, and governments, NGOs and private sector are facilitating not driving.
- **Political leadership.** The need for strong leadership was agreed on by all, but the consensus was that there was also a need that such commitment should consist of much more than making speeches, and that leaders contribute personally and professionally to creating more openness and acceptance, and help to facilitate a climate for positive change.
- **Solidarity among all segments of society.** We are all living with HIV/AIDS (whether infected or affected) - why single out PLHA's? Language can be a powerful weapon in the fight against stigmatization of certain segments of society.
- **Human rights and attitudinal change.** We need both a human rights approach as well as a psychological/sociological approach that focuses on attitudes and behavior around stigma. We do need to have the recourse of rights and laws, but underlying attitudes must also change in order to create lasting change. There has been a gap thus far in applying psychological/sociological strategies.
- **Care and treatment.** Availability of an essential package of care will facilitate the reduction of stigma as well as make it more likely that people will disclose their status.

OPENING SESSION

Preceding the Honourable Prime Minister of Tanzania, the conference was opened with introductory statements by Dr. W. Mwambazi, Chairperson of the UN Theme Group on HIV/AIDS, Tanzania, and H. E. S. Rylander, Ambassador of Sweden to Tanzania.

Opening Address

Hon. F. T. Sumaye, Prime Minister of Tanzania

The Prime Minister provided a well-informed and lucid presentation on the problem of stigma that has accompanied the HIV/AIDS epidemic in Africa. He described stigma confronted by people with HIV in four domains:

- Judgmental and blaming attitudes in their communities;
- Blame and isolation in their schools;
- Discrimination and denial in their workplaces; and possibly worst of all,
- Shame, rejection, and fear in their homes.

While acknowledging that stigma must be urgently addressed, the Prime Minister urged further investigation into the complexity of stigma. In particular, he noted a lack of understanding of the causes of stigma.

> *"If we are going to address stigma, we must first understand it. We should focus our attention on understanding what causes us as a society to react in this way to people living with HIV/AIDS – people who are suffering enough, either physically or mentally to be challenged yet again by the judgement of others. By the very people who yesterday were their neighbours and who should be reaching out to them today. It is only when we understand the cause can we hope to help our fellow men and women react in a more compassionate and humane way."*

He called for a concerted response from the media, religious bodies, people living with HIV/AIDS, health care workers, and political leaders, noting that each of these actors have a unique role and responsibility in reducing stigma. He stressed the need for political leaders to speak out on stigma and acknowledge that they are personally and professionally affected by HIV/AIDS. The theme of political commitment would return throughout the day.

The Prime Minister concluded by saying, "In Africa we are all living with HIV, whether infected or affected. We CAN reduce stigma—by promoting acceptance of people living with HIV/AIDS."

Keynote Address

Mrs Noerine Kaleeba, Community Mobilisation Adviser, UNAIDS

Mama Kaleeba began her address by paying compliments to some of her heroes, those who spearheaded discussions on HIV-related stigma and brought it into the open. In particular, she named Elly Katabira; Sandra Anderson; Eric van Praag; Ian Campbell; David Miller; Helen in Botswana; Kato in Tanzania; Mama Theresa (WAMATA founder). She then asked for a minute's silence in respect of one young hero who passed away only three days earlier—12-year old Nkosi Johnson from South Africa.

Kaleeba delivered her address ex tempore, riveting many audience members by her frank account of her family's experience with stigma. While her husband also experienced kindness while living with HIV/AIDS, stigma ultimately prevented him from returning home to die with friends and family around him. "Although spared HIV myself, I have not been spared the stigma," she noted poignantly.

She also described how communities move through stigma in four waves.

In wave one, there is denial; in wave two, irrational fear, which results in rejection and stigmatization of people with HIV and their families; wave three brings a period of awareness arising from knowledge of transmission that allows reflection and moves us to the last wave, in which communities display tolerance and acceptance.

Communities don't move in a linear fashion from one to the other. She noted that while we have had experiences where communities have moved toward greater tolerance and acceptance, they can revert to the wave of denial before coming back to tolerance.

She also highlighted some of the factors that have helped move us through the waves.

Wave One - denial

- Political commitment and the international red ribbon movement shows that in your daily work you are willing to stand in solidarity with people with HIV/AIDS.
- Surveillance programmes, community level programmes, and the involvement of people with HIV/AIDS and affected families underscore the reality that HIV is a family disease.
- People with HIV/AIDS need to have families, neighbours, and religious leaders to accompany them in this journey.
- The involvement of community gate keepers is also crucial at this stage.

Wave Two – communities moving from denial to fear, rejection and stigma

- Accurate and consistent information, sensitively delivered.
- Comprehensive care and support programmess
- Involvement of people living with HIV/AIDS
- Community discussion of norms and values (our people value the issue of care and support, so we need to get to the community.)
- Clear policy guidelines

Third wave - awareness

- Improve knowledge base on modes of transmission
- Improve awareness about the available options for protection against HIV
- Counter fatalistic tendencies
- Involve people with HIV/AIDS
- Promote positive living

Wave 4 – acceptance and tolerance

- Support and solidarity
- Advocacy programmes
- Community-based care programmes
- Involvement of people with HIV/AIDS and their families
- Involvement of community gatekeepers
- Community-based discussion of rights and responsibilities

Kaleeba also emphasized the need for action to address stigma.

A play on AIDS stigma - "Wewe na Mimi"

The opening session concluded with a drama, "Wewe na mimi—You and Me," presented by the Bagamoyo College of Arts Drama.

The play examines different levels of AIDS stigma and its effects on society. Through Mofa, the central character, the audience is taken through various situations in which we experience how bad HIV/AIDS-related stigma can be.

Mofa is a worker at Octopus Travel Bureau. Her health has been deteriorating for some months and the management decided to give her indefinate sick leave. Mofa goes to her boyfriend who ignores her due to her deteriorated condition. She goes back to her parents. The father puts all the blame on his daughter while the mother feels embarrassed.

At the hospital after all the tests have proved that she is HIV positive, the doctor gives her an early discharge. As the parents cannot stand the stigma of staying with their daughter, they decide to dump her at the village with her grandparents. Mofa feels isolated, unwanted and rejected. She finds no sign of hope and life. She attempts an abortive suicide.

ISSUES AND RESPONSES TO STIGMA AND HIV/AIDS

Defining and characteristing stigma

Links between Stigma, Discrimination and Human Rights

Miriam Maluwa, UNAIDS
Peter Aggleton, Institute of Education, London School and UNAIDS

Aggleton described stigma as an ancient idea with a historical association with illness. He underscored that undesirable differences do not exist naturally but are *created* by human beings. Stigma builds upon and reinforces earlier fears and prejudices (e.g. that HIV is a woman's disease, a gay plague, an outsiders disease) and that it reinforces existing social inequalities and reproduces relations of power and control.

He defined discrimination as the enactment of stigma and stated, "When acted upon, stigma has appalling consequences for the individual…Harm begins when we start enacting stigma." Some discriminatory actions include:

- denial of employment
- denial of the right to marry
- violence and death
- denial right to travel
- segregation in schools and hospitals

Maluwa then presented a human rights approach to addressing stigma and discrimination. Numerous human rights instruments enshrine the freedom from discrimination. Additionally the clause "or other status" in such non-discrimination provisions extends these human rights to people with HIV.

She urged a double pronged approach to address both discrimination and the underlying stigma. She called for action to prevent and challenge stigma and discrimination where they occur and action to monitor discriminatory acts and to provide redress for those affected. Some of the services needed include:

- Establishment of community-based legal aid services
- Training and support for existing legal aid institutions
- Training for members of NGOs and CBOs in AIDS and humans rights concerns

Noting that a human rights framework has limits if stigmatizing attitudes and beliefs persist in communities, she called for the following research priorities:

- Effective strategies for stigma prevention
- Effective strategies for action where stigma persists and is acted upon
- Effective strategies for tackling stigma induced discrimination
- Effective strategies for the kinds of community mobilisation that are effective in preventing and reducing stigma

Overview of Stigma: Definition and Context

David Miller, UNAIDS

Miller provided two definitions of stigma:

- An act of identifying, labelling or attributing undesirable qualities targeted towards those who are perceived as being "shamefully different" and deviant from the social ideal

- An attribute that is significantly discrediting used to set the affected persons or groups apart from the normalized social order (separation implying devaluation)

He noted that HIV-related stigma is often layered upon pre-existing stigmas concerning socially marginalized and vulnerable groups (injecting drug users, men who have sex with men, commercial sex workers, women and children). Conversely, people living with HIV/AIDS may become implicitly associated with stigmatized behaviours, regardless of how they actually became infected.

He also gave definitions for discrimination:

- Any distinction, exclusion, restriction or preference which is based on exclusionary perceptions or structures (e.g., re: race, beliefs, sexuality, gender) and which has the purpose or effect of nullifying or impairing the recognition, enjoyment or exercise by all person, on an equal footing, of all rights and freedoms

- Actions or treatment based on the stigma and directed toward the stigmatized

- Sanctions, harassment, scapegoating and violence based on infection or association with HIV/AIDS

Miller defined stigma as the attitude and discrimination as the act. Similar to Aggleton and Maluwa, Miller described stigma as something that reinforces power relations and existing inequities. He stated that stigma arises from ignorance, from moral systems, and from fear. It is maintained by ignorance and fear as well as by rhetoric, existing power structures, shame and shaming, not taking responsibility for actions, and a focus on HIV/AIDS technology.

He noted, in contrast to Maluwa, that even stigma not acted upon is harmful,and that responses to stigma must focus on the attitudes if behaviour change is to occur. He acknowledged that human rights and the law set a context for redress and change, but criticized the law for being a slow thing and imperfectly applied.

Systems for redress are insufficient, he noted. He called for political will and noted problems of stigma within the health care system. He also called for more investigation into stigma, saying, "To fight stigma, we must name it and measure it. We need to do this before we can combat stigma at scale."

He concluded with the following recommendations:

- Conduct public information campaigns and community forums aimed at promoting tolerance, compassion, understanding, and the reduction of fear, stigma and discrimination.
- Encourage participation of people living with HIV/AIDS in public information campaigns and in HIV programmes and policy formulation.
- Establish more VCT services, including in rural areas and for marginalized groups.

- Support governmental agencies, NGOs and community based organizations to make community-based services, including VCT, family outreach, community support, positive living, support groups, and care options more widely available.
- Encourage the media to report on HIV/AIDS in a responsible, non-stigmatising, non-discriminatory and non-sensational manner.
- Train health care workers in the management of HIV and universal precautions, in attitudes of non-discrimination, acceptance and compassion, and in the principles of confidentiality and informed consent.
- Train other professionals (social workers, police, lawyers, judges) in attitudes of non-discrimination, acceptance and compassion, and in the principles of confidentiality and informed consent.
- Train key personnel in non-health employment settings, including human resource management in industry, in promoting non-discriminatory practices in the workplace.
- Enact or reform laws, administrative guidelines and professional codes of conduct to prohibit discrimination and breaches of confidentiality related to HIV status.

Stigma and HIV/AIDS in Africa: Review of issues and responses

Nadine France, Health & Development Networks

France presented the background document for the meeting which consisted of results of a literature review and focus group discussions and key informant interviews with health care workers, including doctors, nurses, counsellors and traditional healers, people living with HIV/AIDS, religious groups and the media. The majority of focus groups participants and key informants were from Botswana, Tanzania and South Africa, but also come from interviews with people from Ghana, Malawi, Rwanda, Lesotho, Uganda, Zambia, Cameroon and Zimbabwe.

She noted that HIV is stigmatized because it is related to sex and promiscuity. Stigma is, however, perpetuated by a lack of treatment. Although other presenters mentioned stigma in relationship to fatal diseases, France was the only one who put it in terms of lack of treatment. Included in the review was also the views of those who participated through the Stigma-AIDS e-mail discussion forum (a four-month structured discussion on stigma and HIV/AIDS with 1230 members). She suggested possible operational research questions in each of the areas covered, health care workers, religious sector, people living with HIV/AIDS, political leadership and the media (full background paper available on www.hdnet.org).

Consistent with studies on stigma in other parts of the world, the health care setting was identified as the most frequently cited context for experiencing stigma by people living with HIV/AIDS. Health care workers also have the ability to guide community attitudes because of their social position. She noted the following as reasons for stigma in the health care setting: lack of knowledge and skills; personal judgmental reaction; fears of HIV infection; lack of confidence to support emotional reaction to a positive diagnosis; being reminded daily of vulnerability to HIV infection; helplessness - resulting from poor counselling skills, lack of time or lack of treatment options; and work overload.

She also noted the potential of traditional healers to bring communities together, rather than ostracize people with HIV, because they provide group-oriented care rather than the individual –focused care of the western health care model. France then outlined some strategies to reduce stigma at four levels – the care provider, the client, hospital management and the community/family. She also outlined some specific research questions in relation to the impact of voluntary counselling and testing on stigma.

She noted that self-stigma after diagnosis is common among people living with HIV/AIDS and can lead to intense feelings of guilt, depression and a decline in physical health. She also identified the importance of recognizing several distinct levels of disclosure that each require different strategies:

- Intimate level: disclosing to one's partner, family or friends.
- Social level: to access social, spiritual, or health care.
- Public level: personal testimonies and open discussion of the impact of HIV on lives.

Like the Prime Minister, she noted that stigma at the family level is the most devastating and hard to tackle, pointing to the need for special emphasis on stigma experience by children affected by HIV/AIDS.

She also discussed the role of the religious sector in creating and reinforcing stigma. However, she also noted their potential capacity to provide unique care and support and suggested a number of operational research questions.

Regarding the media, she noted the responsibility of the media to be sensitive in their reporting and suggested that the media be informed and become involved in combating HIV/AIDS stigma, themes that would return in the next day's session on communications and stigma.

She also noted the need for political leaders to discuss HIV openly, sensitively and rationally. She emphasised the importance of mechanisms to measure stigma and the need for indicators. She also mentioned some of the gaps in existing tools.

She ended by outlining a list of conclusions following the literature review, the group and key informant interviews and the e-mail discussion saying that we can live with HIV, but we cannot live with stigma. She called for the need for a psychological approach to better understand and address stigma, in parallel and complementary to a human rights approach that addresses discrimination.

Working Group 1: Definition and Context

A 10 minute facilitator summary was presented based on e-mail discussion forum and background documents. Following is a summary of the considerations made by the working group on definition and context.

1. Working Definition

HIV-AIDS related stigma is a real or perceived negative response to person or persons by individuals communities or society. It is characterized by rejection, denial, discrediting, disregarding, underrating, social distance, etc. It frequently leads to discrimination and violation of human rights.

2. Contexts and levels where stigma occur

Underlying factors	Conduits	Manifestations
Fear	Moral values	Disregarding
Ignorance	Inequalities	Denial and inequitable treatment of others
Misconception about transmission, etc ---------→	Prejudices	Rejection, discrimination and the abuse of human rights
Suffering		Social distancing, and a refusal to 'engage'
		External/self (internalized, disengagement, depression, etc) Leads to discrimination and violation of human rights

Generic context

Family	Community	Heath institutions	Public domain Government, businesses, faith-based institutions, media

3. Research questions

- What forms does HIV/AIDS-related stigma take across different East and Southern African cultural groups, communities and countries?
- What are the common characteristics of HIV/AIDS-related stigma in East and Southern Africa?
- What are the determinants of HIV/AIDS-related stigma in different contexts?
- What 'best practice' models of stigma reduction are there that can influence interventions and programs.
- How do we understand better the relationship between stigma, discrimination and human rights in specific settings?
- What factors work best in reducing HIV/AIDS-related stigma as it affects children?
- What culturally acceptable approaches can be used successfully to reduce stigma?
- What factors have enabled some communities to overcome and move beyond stigmatising responses to HIV/AIDS?

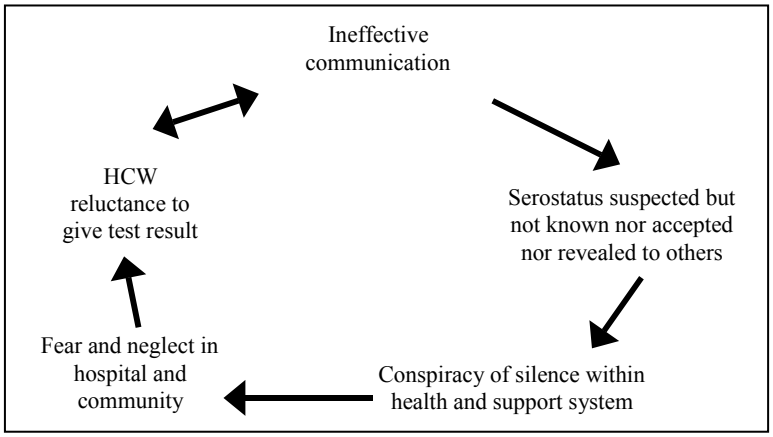
Stigma and the Health Sector

Stigma and the Health Sector

Dr Gloria Sangiwa, Family Health International

Sangiwa presented on the issue of stigma and the health care sector, pointing out its manifestations and proposing possible interventions at three levels, including those in the health care setting (providers in private and public health care facilities such as clinics and hospitals), traditional healers, and home-based care providers.

Manifestations of stigma in the health care setting include:



- Stigma starts before HIV testing in most cases
- Inability to break news
- Immediate discharge after test
- Withholding results until discharge
- Denial of appropriate level of care
- Selective use of universal precautions—only used in suspected cases of HIV infection
- Labelling
- Segregation/Isolation

Sangiwa explained how a "conspiracy of silence" leads to fear, missed opportunities, and barriers to access. She presented a descriptive slide to illustrate this vicious circle:
Health care workers are seen as a "special group." They are role models, both at the work place and in their communities. As a result, others feel if they stigmatize, why shouldn't we?

However, she noted that health care workers can provide support (particularly with counselling). They have a high social and professional status and through this role, they can redress the imbalance of stigma by providing empathy, time, and support.

Currently, attitudes, practices, and beliefs of health care workers include judgmental reactions, a sense of helplessness for failure to cure disease, anger over undue prominence relative to other diseases, and resentment of overemphasis on confidentiality to point of "secrecy".

Health care workers fear being infected at the workplace, not being equipped to deal with their patients' emotional reaction, their own vulnerability and inevitable death. Health care workers face a number of practical and resource constraints:

- Lack of knowledge and skills on HIV/AIDS clinical management and counselling.
- Lack of drugs (anti-retroviral and for opportunistic infections).
- Lack of supplies (e.g gloves, test kits etc).
- Lack of conducive environments and infrastructure to support the complex counselling and treatment regimes.

Sangiwa stressed the need to focus on stigma manifestations that have direct impact on the efficacy of public health.

Immediate interventions:

- At the client or patient level, we can promote disclosure of results to significant others. We must normalize this behaviour while protecting confidentiality. We can form patient support groups (e.g. in TB and HIV wards in Thailand and Uganda).
- At the care provider level, we can promote openness while protecting confidentiality and can ensure that providers have the time and space to empathetic and supportive. Hospital management can help health care workers at all levels to break the silence, provide supportive counselling, care for carers to avoid burnout, and provide knowledge of benefits/barriers to VCT.
- In communities, forums can be created where community leaders and health care workers formulate policy with a stigma perspective.
- In the intermediate and long term, we can design a practical guide for in-service orientation and sensitization tool and build motivation and awareness among health care providers to recognize and avoid stigmatizing behaviors. We can also provide practical tips on stigma-reducing behaviours, adapted to the local health care reality, and conduct intervention linked research to better understand the potential impact of antiretrovirals on reducing stigma.

She concluded by emphasising that the challenge we have today is how to use Hippocratic oath to protect patients and to combat, not perpetuate stigma. She also stressed the need to promote openness and to use health care workers in advocacy.

VCT in the Context of Stigma

Jessie Mwambo, Muhimbili Voluntary Counselling and Testing Clinic

Mwambo started by saying that addressing VCT in the complexity of stigma is a challenging endeavour. There is a need to look at stigma at various different levels and contexts to understand how this plays into the VCT settings. It involves:

- Clients' decision to come for VCT
- The VCT clinic setting
- The VCT process
- How the VCT process influences the period after the post test

Decision to come

- What community awareness campaigns are in place and what are the messages? For example, "one of these young people has HIV" (the poster with all girls is stigmatising to women).
- Who sent the client and why now (self referral vs. institutional referral)?
- Why did the client decide to come? What are the perceived benefits and risks (with women associated risks, e.g. partner violence)?

The counselling clinic

Where is it? Is it far/hidden, like the leprosy or Pulmonary Tuberculosis (PTB) wards? How is the sign posted? What is it called? Does clinic offer comfort and privacy? The clinic is often small and says "you need to be punished." What type of counselling staff are there and is staff burnout addressed? Is there a standard time period for the VCT process?

The VCT process

Registration of the client is often shrouded with secrecy. It is anonymous whereas other clinical related tests use names. The client is often seen alone by the counsellor, unless he or she comes with a primary partner or is a child. Only sometimes, the client is brought by concerned relatives.

Pretest counselling procedure

- Difficulties in discussing taboo issues (blood, sex, death) that are not in keeping with culture (e.g. gender and age).
- Assess understanding of HIV, correct misperceptions, and previous contact with VCT. How do counsellors view repeat testers?
- Risk assessment places blame on sexual practices, preferences, or desires and number of sex partners (men who have sex with men, wet/dry/oral sex). Yet counsellors may be practicing the same behaviours themselves.

Pretest counselling

- Informed consent has a negative connotation (as well as positive). It is often signed and specifically states disclosure-related issues. This contrasts with group involvement in care in group-oriented communities (signing to get test done when by yourself).
- Confidentiality and shared confidentiality is contrasted with regular group-oriented health care.
- Emotional coping mechanisms and support (linking with family when illness has behavioral causality and thus guilt, shame)

Post test counselling

- Putting person being counselled at ease
- Make environment for receiving test conducive (extra effort unlike other clinical related tests)
- May need to postpone if client not ready
- Allow for self reflection of the client
- Use of condoms to control infections
- Disclosure of test results to significant others
- Why did you to go to VCT in the first place? (Issues about past sexual behaviours)

In conclusion, Mwambo stated that HIV VCT is an important entry point for the prevention, care, and support continuum. Conflicting and stigmatising messages and processes pre, during, and post VCT have furthered the culture of silence and secrecy around HIV/AIDS. The way people perceive HIV/AIDS has increased the social distance of those affected *(serious, contagious and behavioural causality)*.

It is important to open dialogue in VCT and look for ways of including the immediate supporting community for those affected. To be able to do this we need to have a better understanding of the process from decision making to entry and exit from VCT taking into account African communities are not nuclear while the VCT is client-oriented therapy.

Recommendations:

- Assess longitudinally people who access VCT over period of time. Start before pre-test see whether people are self stigmatizing and/or experience stigma from outside.

- Assess to what extent the surrounding environment perpetuates stigmatisation within VCT settings and how we can intervene.

Working Group 2: Stigma and the Health Care Sector

A 10 minute facilitator summary was presented based on e-mail discussion forum and background documents.

1. Priority areas causing HIV-related stigma

• Practical and attitudinal HIV related training for all health care providers (HCP) • Promote VCT care and support for HCP • Establishment of and mainstreaming AIDS care within the existing health systems and development of discharge and referrals systems that are not stigmatising to patients • Scaling up of youth friendly health services
Professional specific areas causing HIV-related stigma

Doctors
• Inadequate skills related to HIV-related issues
  o Clinical management and counselling
  o Fear of failure of treatment
  o Coping and dealing with sex and death
• Overwhelmed by workload
• Fear of infection
• Denial of appropriate treatment
• Pass responsibilities to others: Nurses/Social workers/Counsellors
• Confidentiality conflicts
  o Discordant couples
  o Death diagnosis: never AIDS why
• Limited resources
  o Human, financial

Nurses/midwives
• Fear of risk of infection at workplace - take universal precautions overboard • Burnout • Low morale • Resignation • Inadequate care and support for those within the profession who are infected
Counsellors/Social workers
• Inadequate information and skills in working in the area of HIV/AIDS • Lack of recognition of counsellors as evidenced by no salary and results in low morale • Overworked due to work being dumped on them thus self stigmatizing and become stigmatizers • Burn out
Volunteers
• Inadequate information and skills on HIV • Lack of standardized home-based care kit to assist in care • Lack of continuum for care • Inadequate skills for maintaining confidentiality

With reference to professional code of ethics and conduct of HCP:
• Code of ethics and conduct in health care provision are in place • Code of ethics not upheld because environment makes it difficult • Workplace should be conducive for the worker to make it possible for the HCP to uphold the code of ethics and conduct • Transformation of person and not penalizing HCP for failure to uphold code of ethics and conduct Due to the limited awareness of rights there is need for: • Awareness creation of service providers • Awareness providers for those utilizing services

2. Specific operational research questions on stigma and the health sector

- To what extent is stigma present amongst HCP?
- What are the determinants of stigma among HCP?
- What operational research needs to be done to address these determinants?
- Does access to specialized provision of care and support reduce stigma?
- Does development of links between clinical and community based facilities reduce stigma?

3. Existing interventions that could reduce stigma

- Case studies in Uganda
    - Integration of comprehensive package of care for PLHA within hospitals (Mulago) linking with CBO (TASO) that have been scaled up to district hospitals
    - Mother-to-child (MTCT) interventions
- Training programs
    - Basic information and counselling skills on HIV/AIDS
    - HBC workers in the management of HIV and universal precautions, in attitudes of non-discrimination, acceptance and compassion, and in the principles of confidentiality and informed consent.
- Youth-friendly services
- Using PLHA as trainers (will need to be explored further)
- Coping centers
- Caring centers for HCP
- Prophylaxis
    - Post exposure prophylaxis (PEP) for sharp injuries
    - Ioniozed (INH) prophylaxis for tuberculosis
    - Pnuemonia (PCP) prophylaxis for bacterial infections

4. New interventions to reduce stigma

- Improve information, skills and attitudes to HIV/AIDS of HCP
- Improve resources
    - Human
    - Financial
    - Continuum of care
- Improve institutional bottlenecks so as to improve
    - Training of HCP
    - Caring for carers (PEP, INH, psychological)

- Facilitation of openness about HIV/AIDS will indirectly improve on stigma

5. Key interventions that could be scaled up.

- Practical and attitudinal HIV related training for all HCP
- Establishment and implementation of AIDS referral clinics where HCP are exposed to discharge systems that are not stigmatizing to patients
- Promote VCT care and support for HCP
- Scaling up of youth friendly services

Family and Societal Stigma

Stigma and People with HIV/AIDS:

Scovia K. Nabagala, NACWOLA

Often at the receiving end of stigma, people living with HIV have first hand experience with the ramifications of stigma and also with the more positive examples of interventions that have helped to reduce felt stigma. Scovia Kasolo Nabagala, Chairperson of the National Community of Women Living with HIV/AIDS in Uganda (NACWOLA) gave an overview of how stigma directly affects people living with HIV, followed by a description of self-stigma, and then family and societal stigma. She then explained how NACWOLA has contributed to the reduction of stigma in Uganda. She concluded by suggesting areas of operational research.

Stigma, she said, is one of the major challenges that people with HIV/AIDS face. Stigma, silence, discrimination and denial undermine prevention and care strategies and increase the impact of the epidemic on an individual. Stigma is most deeply felt when someone has just received an HIV positive diagnosis. From personal experience, she added, this could be due to the emotional struggle within oneself i.e. fear, shock, anger, depression, frustration, denial bargaining and asking oneself "How will people look at me?" There are many reasons – internal and external - why people feel stigmatized.

SELF-STIGMA is internal. It begins with an individual not seeing the benefit of living and looking at him/herself as unfortunate and contemplating what other people are going to think about him/her. "You are always conscious about your appearance and health status and always checking for signs that will alert others that you have HIV."

She described her personal experience, " as a nurse, before I disclosed my status I kept injecting myself with medications just because of fears I had of being stigmatized and the feeling that the health workers might suspect I was HIV positive if I went to the clinic... I also know of a friend who called me when she had a pimple and feared to go out of her house in case people would be alerted that she has HIV." Self-stigma is partly caused by fear of how other people will relate to you – fearing denial, exclusion, loss of property, employment, educational opportunities, eviction, and abandonment by friends.

SOCIETAL STIGMA refers to societal attitudes and norms that stigmatize people living with HIV. The individual often feels forced to do a 'self withdrawal' for fear of being judged, ostracized or shunned. An example is the societal attitude that 'AIDS is for prostitutes, for people who have nothing to offer.' In order to support PWHAs to cope and live positively, it is important to understand and address these issues both at personal and societal level.

The role played by PLHAs in stigma reduction should be underscored. However, she added, we must be reminded that we really need to show HIV/AIDS wearing a "professional and skilled face". It is this which can sway opinion.

In talking about FAMILY STIGMA, she noted that it takes a lot of courage to open up to family members making them understand and appreciate the dilemma you are in, as many of them may relate your situation to your past behavior. Some of them may relate past deviation from expected behavior in society to your current predicament. The situation is worse when it comes to your immediate and close family members like your children whose understanding, depending on age, is limited to the obvious facts of life. These difficulties heighten the fear of opening up to one's family and impede the individual's ability to cope with HIV.

Family level initiatives, like NACWOLA's Memory Project, has helped in reducing stigma especially stigma related to children. The Memory Project aims at helping parents living with HIV face the reality of living with HIV and openly discuss the situation with other family members especially the children.

As a conclusion, Nabagala suggested the following as important research issues:

- What is the role of disclosure in fighting stigma?
- What are the effects of HIV-related stigma on individual, family, community, and children?
- What are the predisposing factors to self-stigma and are they uniform or do they vary from community to community?

Stigma, Children and Youth

Stefan Germann, Masiye Camp, Salvation Army

Germann opened his presentation by arguing that we need representation of children's own views on stigma at this discussion. The Salvation Army conducted focus group discussions with 95 children in May 2001 to do just that. These focus groups explored how youth and children perceived the causes of stigma and how it could be reduced. Some ways included reducing ignorance in the community as well as developing children's own self-esteem and life skills.

Children's perspectives are critical because the projections of HIV/AIDS orphans are expected to increase drastically. This is not only an argument of numbers. We are now facing the risk of an entire generation of children growing up to adulthood with chronic stress and trauma, potentially leading to dysfunctional societies.

Although this scenario is daunting, Germann pointed out that there is a richness of resources among children.

> *"We know that we lack money, but all of us, we have a heart to understand the distress and grief of these children, eyes to see, ears to listen to them and we have words to talk with them. We have a smile and we have time. These resources are for free—and they may be among the most powerful resources to protect the "capital of social energy", motivation and self-confidence in this young generation, for their own benefit and of the whole society" (Humuliza/Kagera Manual)*

He then described the Masiye Camp approach, which includes key elements of psycho-social support for children affected by HIV/AIDS and orphans (and is a UNAIDS best practice). He concluded with a call for research on:

- Assess the impact stigma has on the quality of life for children and youth – Adapt WHOQOL standard psychometric tool
- Longitudinal programme impact research on psychosocial support initiatives
- Youth and child participation in programming
- Effectiveness and impact of life skills education to cope with stigma
- Impact of stigma on behaviour change

Addressing Stigma and Disclosure in the Workplace

Eka-Esu Williams, Population Council

Williams presented a qualitative research project conducted by Population Council in South Africa. Among the workers and managers studied, there was a strong association between HIV infection with stigma related to promiscuity and prostitution, and a strong association with hopelessness and death. Blame was targeted toward women and girls for spreading HIV.

Researchers found that counselling support was necessary for disclosure. There was a need for confidentiality after disclosure, and the person disclosed to often needed education and training. Women feared disclosure would result in rejection and violence.

Within the workplace, gossip and rumours were the most frequent occurrence of stigma, resulting in self-stigma and secondary stigma. There was an association between the onset of stigma and the progression of symptoms. However, there were strong feelings that people with HIV should be cared for. Respondents were more concerned with stigma in the home than in the workplace.

The study recommended interventions for the workplace:

- De-emphasize symptoms in training curricula
- Train managers to deal with disclosure and stigma
- Involve PLHA's in intervention activities
- Include disclosure and stigma issues in training for counsellors, managers, social workers and others
- Referral for infected and affected persons to support groups, counsellors and social workers
- Train medical staff on issues of stigma and disclosure
- Devise strategies for addressing secondary stigma experienced by PEs and counsellors

And for the community:

- Provide support to families and care givers
- Strengthen referral mechanisms for PLHA to support groups
- Challenge negative beliefs and perceptions on HIV/AIDS
- Emphasize couple counselling to reduce violence and blame directed at women
- Train and sensitize church leaders and traditional healers to address stigma and disclosure
- Include stigma and disclosure issues in training of NGOs providing HIV/AIDS services

Working Group 3: Stigma and People Living with HIV (with special emphasis on children and families)

A 10 minute facilitator summary was presented based on e-mail discussion forum and background documents

1. Priority issues on stigma and PLHAs

- There are different levels of stigma in different societies. We need to be able to diagnose the level before doing something to address stigma. For instance, disclosure needs to be tailored to specific form of stigma practised in family/community/country.
- Choosing the time and place and ensuring support is vital in the context of stigma when disclosing a positive status.
- There is a need for effective, ongoing and compassionate counselling, focused on the family and not only the individual. Western counselling models have not been adapted to suit the African context where the family must be an integral part of the process.
- A lack of integrated support services for PLHAs was highlighted
- An essential package of care is needed to reduce stigma and provide adequate care for PLHAs. This package should including basic HIV testing and counselling, early diagnosis and treatment of opportunistic infections, nursing and nutrition and psycho-social support for all the family.
- "Every country should provide this full package as a minimum – otherwise they are not fit to call themselves a country" (Noerine Kaleeba)
- The low involvement of HIV-positive professionals in AIDS work as a result of fear of stigma and discrimination, leads to a limited skill base in PLHA organizations.
- Tokenism involvement of PLHA combined with lack of support for projects and initiatives planned by PLHA organizations leads to resentment and anger.
- There is a need to move from the term people living with HIV/AIDS to reflect people affected by HIV/AIDS, which includes partners, children and other relatives and friends. In this way, interventions should also make this shift from the individual to the family and wider community.

2. Existing interventions to reduce stigma

- Experience-based training provides not only information but also focuses on feelings, values, attitudes. This training often provides practical skills to help people deal with difficult situations.
- Effective culturally-appropriate counselling that encompasses compassion, a focus on the family, a continuous service and an approach that helps transform anger into effective action.
- Holistic, community- and family-centred approaches to HIV/AIDS action which builds on leadership, initiative and organizational resources within the family and/or community. Government and NGOs need to play a facilitation role rather than a driving role in this.
- Prevention needs to be relationship-based and linked to care in order to change behaviour and attitudes. Where this is not the case, it is possible that interventions can lead to increased stigma.
- Skills building among PLHA, with a focus on education, advocacy, media work, management, reporting, etc.

3. New interventions

- A checklist to assess the level of stigma. This should be a diagnostic tool that can assess the level of stigma within a family/community which will be useful in counselling, disclosure, community organisation, advocacy, etc. Checklist could be used to read the situation at national, community, or family levels.
- A strategic approach to disclose that prepares people for how, when and where they should disclose.
- National policies for essential package of care, where each player has clearly defined roles. Government, NGOs, PLHA organizations etc. Governments should provide the policy framework and coordination.

Stigma and the Religious Sector

Stigma and the Religious Sector

Ian Campbell, Salvation Army

Campbell provided the conference with concrete examples where interfaith dialogue and cooperation in relation to HIV/AIDS clearly illustrate the linkage between care and change within families and neighbourhoods.

- In 1998, a 'Conference on AIDS and Religion' was held in Senegal. After a presentation by a Christian organization of community and home-based approaches within countries such as India, Haiti, Kenya and the Philippines, an Imam commented: 'We can work together in the community. We believe in family and reconciliation with God. You believe in relationship between people representing the process of relationship to God. Government is promoting community ownership which depends on good relationship. We can all share on this point.'

- In Hikkadua town, south of Colombo, Sri Lanka, a Christian team which has been doing home care in Buddhist neighbourhoods for four years has recently been invited to the local Buddhist temple to facilitate discussion between members of the local community.

- The Africa Regional Forum of Religious Health Organizations in Reproductive Health is based on partnership between religious health networks, Christian and Islamic. The Forum, facilitated by International Family Health was launched at the International Conference on AIDS and STDs in Africa, September 1999.

These and other examples represent increased confidence within secular organizations to explicitly affirm, respect, and engage with religious organizations, faith-based communities and persons of faith. People have a personal capacity for faith. This capacity needs to be respected as a key strategy for going to scale.

Campbell noted that we can mobilize faith-based communities in taking their part in responding to HIV/AIDS; the first distinction is between religious structure and personal faith. When these get mixed up we are paralyzed. Religious structures can be very suppressive/repressive, but a counterpoint to that are individuals with high personal faith who respond.

He outlined some of the key lessons on the experience of some faith-based responses in reducing stigma?

(1) Care

This is usefully characterised as a supportive presence that accompanies people in their situation, for example, visiting a neighbour or a community visit. Care is sometimes named as 'love in action'; it includes mutual support between family, neighbours, community, and a relationship of being with and interacting with others. This understanding is in contrast to the common view that care is provision of treatment.

(2) Change

Change occurs by seeing care (or experiencing care), which leads people to acknowledge the reality of HIV, and may result in a change in understanding and attitude. Care helps to make change more likely to happen especially when care is explored in the home setting. Change does not happen simply in persons in isolation but when the care and change process is relational in nature, change is expansive. It is a foundation for going to scale, and for organizational and institutional adaptation, as a contributing influence in scaling up response.

(3) Link between care and change

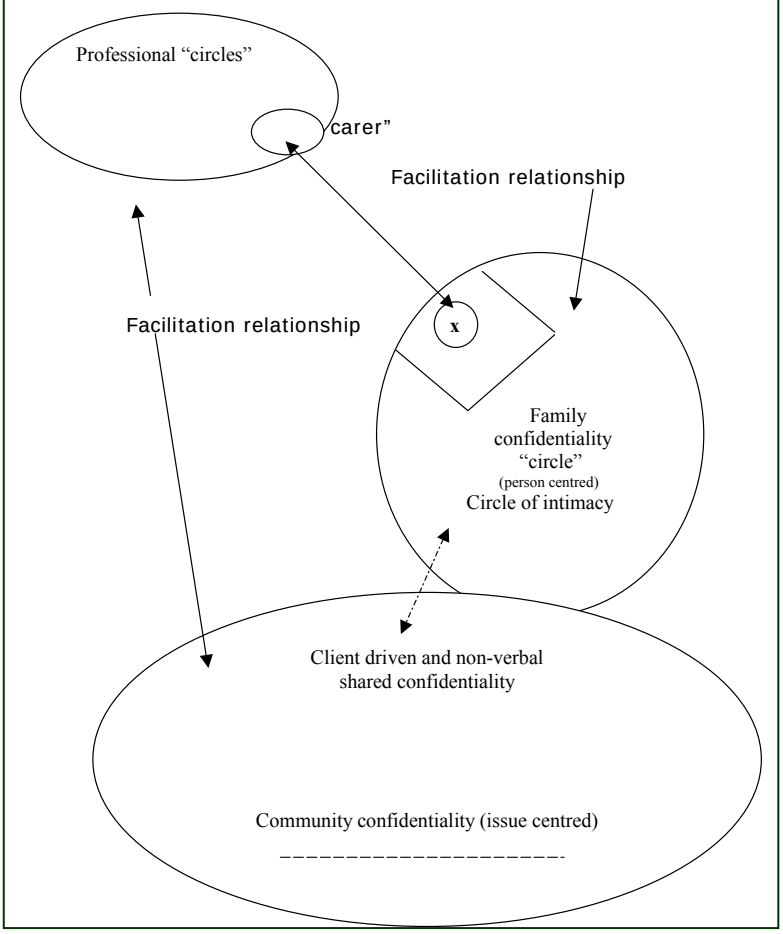
The link between care and change is relational. Care that is personal and is observed by people in the household and neighbourhood, can generate motivation and action for shared change. This can rapidly shift a situation from stigma to shared responsibility for change around issues of mutual concern. *(See figure 1)*

The care to change linkage is also termed 'care/prevention' linkage. It is a key strategic approach to expansion of circles of involvement in local community and organizational responses to HIV/AIDS.

(4) Distinction between public disclosure and shared confidentiality Shared confidentiality is shared knowledge and understanding of meanings within a context of respectful intimacy within a group in which there is a sense of mutual accountability. Knowledge that is shared in this context is not a secret. The content and meanings are known within the group, even though there is not necessarily open conversation about the content and meanings.

People in local neighbourhoods live in an environment of shared confidentiality, referring to the inevitable diffusion of information that helps shift secrets to shared knowledge, shared understanding and shared safe intimacy, which

Figure 1: Shared Confidentiality
A Pathway to Stigma Reduction



is a confidential environment. Recognition of this community capacity is an entry point to disciplined community counselling, which can rapidly accelerate commitment toward prevention processes by local communities, as well as to care for each other. *(See figure 1)*

It is possible to counsel a community on the basis of shared confidentiality, without HIV positive members of the group having to verbally disclose their status, and this has been found to be an effective environment for stigma reduction and normalisation.

The person-centred nature of the confidentiality experienced in a home can shift to issue centred confidentiality in a community discussion which helps share responsibility and influences prevention in the whole group.

Campbell concluded his presentation by presenting a number of operational research questions:

(1) What are the characteristics of an integrated care and prevention approach that allows for conflict resolution and results in stigma reduction?
(2) Within the local community experience, how can personal faith be explored, respected and affirmed as a fundamental strength for community response and destigmatization?
(3) Regarding partnerships of the religious sector (with other organizations), how can theological principles and identity be expressed respectfully, and linked to practices that are encouraged by the partners (such as counselling, community choice making in behaviour change, harm reduction, family protection etc.)?
(4) What evidence exists that organizational response can be accelerated by community participation approaches that involve people, including leaders, from the religious sector?
(5) What is the impact of accumulating loss in families and communities? How does faith and future hope interrelate with the accumulating loss?
(6) How can capacity for shared confidentiality within groups be linked to scaling up both care and prevention action and impact?

Stigma, HIV/AIDS and Religion in Namibia

Sister Raphael Handler, Catholic AIDS Action

Handler provided examples of interventions in the religious sector in Namibia. The first four HIV-positive persons were diagnosed in 1986. By 1996, AIDS became the first cause of death in all 13 political regions. Sentinel surveillance in antenatal clinics (bi-annual) show that figures are still rising. In 2000, the prevalence on a national level was 22.5% and the highest prevalence was 34% (31% in Windhoek). There is also a growing problem of AIDS orphans.

More than 90% of Namibians are Christians with the Lutheran churches being strongest. More than 50% belong to one of three Lutheran churches. Roman Catholics are about 50% of the population.

She informed participants how in February 1998 a decision for a new community-based national programmme was made by the Namibian Catholic Bishops‘ Conference. Bishops recognised HIV/AIDS as the number one problem for Namibia. The programmme is a programme of action, not moral teaching. As of 1998, Catholic AIDS Action has a national programme, “The courage to Fight, The Strength to Care” with eight regional offices. It focuses on awareness, prevention, and care. It is based on Christian values and works with trained volunteers from parishes. There is no discrimination between Catholics and any other denomination. It provides both physical and spiritual support. She told how the Archbishop Haushiku spoke out with a powerful statement saying, “AIDS is a disease, not a

sin; though some might acquire the disease through sinful behaviour." Infected and affected people have to be treated with love and respect, not discriminated against. Jesus is the example. Catholic AIDS Action develops material for awareness and training material for trainers and for volunteers. It is always stressing the dignity of the person, who needs respect and love.

In 1999, Catholic AIDS Action held a National Conference: Living positively with HIV/AIDS. HIV-positive persons give testimony in the presence of the President and Archbishop in the Roman Catholic Cathedral. Living Positively Conferences were broadcasted on a regional level in local languages.

Catholic AIDS Action also participated in the 2000 March of Hope. It raised the awareness of problems specific to orphans, particularly stigma, with the Prime Minister, Mayor, and churches. It also participated in the June 2001 conference on home-based care where the theme was caring for the carers ("Caring for others in order to care for ourselves").

A 1999, a Bishops decree stated that within three years all parishes should start an AIDS programme. The 2000 Bishops decree stated that an AIDS message should be included at all major events. "The Love your Neighbour" booklet was developed for spiritual care.

She described a Drop-in-Centre in Windhoek; providing free legal advice in cases of discrimination and a programme started in 2001 with Family Health International to keep orphans in school. It has a destigmatization component for psycho-social training of teachers and care givers.

She proceeded by giving examples of interventions of the Catholic Church of Namibia (CCN) and other churches include:

- Pastoral letter of CCN in 1999 acknowledged that AIDS is a problem and stated,"AIDS is a disease, not necessarily a punishment. Discrimination has no place in our churches".
- Meetings for pastors on how to deal with AIDS patients
- In 2000 a desk for HIV/AIDS
- Two Lutheran churches are in the process of starting a programmme
- Namibian HIV/AIDS Charter of Rights

Raphaela concluded by presenting her suggestions for ways to combat stigma within churches:

- Education, information on the disease to the church leaders
- HIVpositive people giving testimony in their congregation
- Recruiting and training of members of congregations how to care for sick persons
- Awareness programmess, training in counselling skills within the training of church leaders
- No ordination without home care of HIV clients
- Healing services
- All efforts, not to be judgmental
- Indicators for stigma within religious groups
- Study the relationship between stigma and gender inequalities within rel. Groups
- Study difference between Christian churches and other religions, i.e. Islam
- Find examples of religious groups where stigma decreased , reasons why
- Study the relationship between strict moral teaching and stigma/ discrimination

Working Group 4: Stigma and the Religious Sector

A 10 minute facilitator summary was presented based on e-mail discussion forum and background documents

1. Priority issues on stigma and the religious sector

- Shame and guilt linked to culture and religious values and teachings
- Stigmatisation among religious leaders
- Religious communication strategy - avoiding stigmatising value loaded vocabulary
- Community stigmatisation

2. Operational research questions

- What is the level of knowledge, attitude and practices of religious leaders about HIV/AIDS?
- In what ways do religious leaders stigmatise and discriminate as perceived by communities?
- In what ways do members of the congregation (community) stigmatise/discriminate against individuals and families affected by HIV/AIDS?
- How are shame guilt and isolation fueled by religious teachings and values?
- To what extent do religious values and teaching help to reduce stigma?
- What is the source and extent of HIV/AIDS-related stigma?
- What is the damage done to those experiencing stigma?
- How can religious leaders and groups be influenced to give accurate information to members of their communities?

3. Existing interventions

- Home-based care programmes
- Support groups (PLHAs & HBC Volunteers)
- Care for orphans
- Faith-based counselling
- IEC for leaders and communities (including HIV/AIDS issues into sermons, crusades etc.)
- Care for terminally ill
- Sharing by people who are affected by HIV

4. New interventions

- Integration of HIV/AIDS information into all religious leaders training & seminars (where appropriate)
- Identify religious teachings and values which do not promote stigma and reinforce these
- Accepting that AIDS is a disease and not sin
- Needs assessment baseline data

5. Key interventions for scaling up

- Training for both religious leaders, religious groups and communities or identified needs
- Formation of more support groups and ensuring their support

6. Indicators to measure stigma in the religious sector

- Attitudinal changes by the religious entities:

    - Shift from linking judgement to inclusiveness
    - Participation and encouragement in shared responsibility

- Level of action in community activities:
    - Engagement in wider community outside the religious congregation
    - Not necessarily only for the well-being of own religion but also in relation to the wider community

- Level of commitment from the religous sector to HIV/AIDS activities?

Stigma and Communication

Stigma and Communication

Felicity Hatendi, UNIFEF

Hatendi discussed communication efforts and the use of the media to reduce stigma. Her presentation emphasized changing the way we use media to move away from:

- viewing people as objects to be changed toward viewing people and communities as the agents of change.
- the designing and delivering messages to supporting dialogue and debate on the prevailing HIV/AIDS stigma in our midst.
- information from technical experts to sensitively placing that information in public dialogue and debate.
- a focus on individual behaviours to address the social norms, policies, cultures, and supportive environment that perpetuate stigma in Africa.

This emphasis on moving away from a process dominated by technical experts from outside communities to communities guiding the dialogue was a theme throughout her presentation. The active participation and central role of communities was a sentiment echoed earlier in the conference, and would reemerge.

Hatendi saw a real need for research before proceeding with programmes. “We tend to rush to develop messages before we understand the community we are working with,” she commented.

A second theme of her presentation was the forgotten media indigenous to Africa. Media such as African music, spiritual chants and prayer, and traditional institutions (e.g. family unions and burial societies) have been sidelined in favor of radio, TV, and print media. Hatendi urged the use of active and interactive media, which she felt had more impact than passive forms of media.

Stigma, Children, and Youth: Soul City

Sue Goldstein, Soul City

Goldstein described the Soul City programme and presented information on a national survey in South Africa on individual and community attitudes undertaken as part of the research for the Soul City and Soul Buddys programme.

She described the Soul City programme as an edutainment programme that uses TV and radio dramas and print materials to decrease negative attitudes. It is a 13-part, national TV drama, one hour per episode and a 6-part, radio slot, 15 minutes per episode that started in

1994. What is unique about these programmes is that their design relies on audience-centered research. The messages given out promote the idea that people with HIV are not bad, that they have rights and needs, and deserve respect. Other messages dispel myths about transmission of HIV through casual contact to complement the anti-stigma messages. Soul Buddys is a young person's version of Soul City. These programmes are designed based on research with children and touch on issues of stigma in the home, school and church.

Substantial qualitative and some quantitative evidence shows that the Soul City programme has been successful.

"I learned that one should not look down upon one who suffers from AIDS. Your attitude should not change towards one who is ill, the story was full of love…"

In the survey conducted to assist with the development of the Soul City programme, overall, 88% of the 2,000 people surveyed disagreed that people with HIV should be moved away and 72% reported that they would consider helping someone with HIV in some way. Level of education and exposure to media had a negative relationship with negative attitudes. Other individual factors such as gender, employment status, and living in a rural or urban area had little association with attitudes. Age was a factor ($p \leq 0.05$), with older people generally being more likely not to consider helping someone who is HIV positive. Respondents seemed to overstate stigma in the community and reported that they believed their families and communities held more negative views than their own.

In the development of Soul Buddys, additional research with HIV affected children and adults showed that they identified acts of discrimination in the family. They also acknowledged stigma in the community—at school, in church, and in the health care system—and drew links to poverty and to promiscuity.

> *"I fetch water from the river, I am the only one who takes care of the maize field, the only one who is expected to do work around the house." (orphaned girl in rural area)*
>
> *"They treat you badly: you don't feel like walking in the street. They give you names. They whisper when you pass. They take it that when one person in the house is sick, all of you in that house are sick."*
>
> *"People won't want to share a bible of hymnbook even if you are the one who has got them and they don't."*
>
> *"And sometimes a priest doesn't understand AIDS and he influences the congregation."*
>
> *"The other day my child was in pain. I went to the clinic wit her and the nurse said there was no medicine. I was hurt because I could see the medicine behind her."*

Goldstein described how the research is used by programme experts to design various episodes of Soul City for TV an radio to ensure that the programme reflects the realities in South Africa and also help dispel myths and reduce stigma.

Working Group 5: Stigma and Communication

A 10 minute facilitator summary was presented based on e-mail discussion forum and background documents. The following issues were raised as an introductory briefing for the group session on communication and stigma, following up on the Stigma-AIDS discussions, accompanying information on communication and points raised in the stigma meeting discussions on 4 and 5 June 2001:

- Media and communication specialists are strategically positioned to shape public attitudes, views and perceptions with regard to HIV/AIDS coverage and communication
- Media can advocate for improved and accurate communication that is culturally sensitive and can stimulate public debate
- HIV/AIDS needs to be addressed as a development issue, not merely as a health issue – it has wide socio-economic implications
- Regional media coverage of HIV/AIDS over the past few years has increased quantitatively but not qualitatively important to give HIV/AIDS a human face; behind every statistic, there is a human story to tell there are very good examples of media strategies taking place with a multi-media approach, eg Soul City – will this idea work as effectively in other countries?
- Important to target media gatekeepers who are the editors; newsrooms in this part of the region are male dominated, HIV/AIDS seen as a 'soft' issue, therefore written by women and relegated to the back pages of the publications – important to mobilise women to break the glass ceiling in the newsroom
- Provide incentive/rewards for journalists reporting on HIV/AIDS
- Access to Internet of journalists; e-mail, electronic media
- Need for regular training of all levels of newsroom staff
- Provide new interesting angles and approaches for reporting on HIV/AIDS
- Have some sort of code of conduct; ie interviewing techniques, guidelines, ethics
- Form partnership between media and NGOs fro share/exchange of information
- Expose bad practices such as cultural beliefs and myths, misconceptions, always providing examples
- Journalists should be involved in drawing up legislation – seen as an important body with government in this process
- Make use of alternative media
- Tap into/strengthen existing programmes
- More important to start dialogue than convey messages.

1. Priority issues for stigma and communication

- What to we want to communicate about stigma? Positive messages that provide hope, life and future; should be addressed in an African context; bring out positive and negative experiences
- When should one communicate? All the time, but important to gauge current operations to determine appropriate entry point, ie radio or TV, peak viewing hours might attract large listenership, but most women – an important target group - might be cooking/undertaking domestic chores which take them away from radio or TV
    - positioning the message strategically among other competing messages on HIV and other health issues
- What should be addressed: attitudes, perceptions, values, images, beliefs – important to demystify existing myths, misconceptions, stereotypes

- How? Reinforce positive aspects, not just say stigma is bad, but put measures in place to counter it, be more innovative in approach, use best practices where appropriate; create a balance
    - Develop training for everyone involved in addressing stigma
    - Present people as active agents in coverage; ie information sources, experiences, views, feedback, follow up
- Create two-way communication channels to allow people the opportunity to react (eg Soul City, via competitions, chat columns, telephone lines, e-mail discussion forums, encourage letter writing, eg to editors to spark debate, etc
- Involve communicators, message designers, audience – a multi-sectoral approach; health care workers, religious leaders, media, activist working in HIV/AIDS, policy makers, religious leaders, care-givers, receivers, etc
- Why? To promote positive change, reduce stigma, improve quality of lives for everyone, encourage behaviour, promote open dialogue and communication, coverage of HIV/AIDS

2. Operational research questions on stigma and media

- What media is effective in reducing stigma?
- What is the context? What type of communication is the most appropriate? eg radio programmes for parents and children
- Who is appropriately positioned to communicate about stigma in various settings, eg study in India of social networking?
- When is it appropriate to deliver the message; is there evidence as to when this is most appropriate? Should ask advertisers
- Do we know enough about the behaviour/attitudes of our target audience
- How does my communication contribute to/decrease stigma?
- Which language is appropriate for use? How do we use stigma?
- Need to research target audience, experiences with HIV/AIDS, sex, age, gender, educational background, values, perceptions, beliefs, lifestyles, sexual behaviour Measure effectiveness of media
- Very few studies have been done resulting in positive/negative attitudes and changes
    - Take account of contextual/cultural differences
    - Audience research important before scale up
    - Personnel may differ, resource availability, skills expertise
    - Existing policies may inhibit scaling up, policy environment, most policies are generic, institutions may not have specific policies

3. Existing interventions that could reduce stigma

- Specific existing interventions include:
    - Soul City
    - UNICEF Sara series in East and Southern Africa
    - Twendi na Wakati radio in Tanzania
    - Media Monitoring in Zimbabwe
    - SAfAIDS media programme
    - LoveLife in South Africa
    - Community theatre
    - Straight Talk
    - FEMINA
    - Body Talk, training in life skills in South Africa
    - Stigma-AIDS e-mail discussion forum (Af-AIDS e-mail forum)

    - Community Advisory Board, lay counselling programmes,
    - Health workers for change – gender issues
- Important to develop guidelines for the above to help reduce stigma (UNAIDS), plus HIV/AIDS IEC programmes, Trendsetters in Zambia, campaign in support of HIV positive people, peer education programmes, newspapers, features, stories, radio programmes, PSI.
- UNAIDS communications framework was recommended as a tool that could be used to reduce stigma in communication programmes.

4. New interventions to reduce stigma through the media

- Encourage politicians to raise the HIV/AIDS profile in all meetings, public addresses, etc
- Target media through buying space, lobby newspapers to have a social commitment vis a vis reporting on HIV/AIDS, avoid gutter journalism
- Develop supplements in regular newspapers
- Formation of a media coalition
- Funding of existing projects in order to sustain them; assist in evaluation
- Lobby politicians, role models, personalities to keep HIV/AIDS in the public agenda
- Lobbys PLHAS with media initiatives
- Develop interactive radio/soap/TV series – seek audience response/participation, response and feedback
- Private sector collaboration – i.e. lobbying beer companies, targetting insurance companies
- Journalism training at polytechnic, college, training institutions
- specialised journalism
- View HIV/AIDS as a development issue, not merely a health issue
- Develop adult literacy programmes
- Revival of traditional media for local communities amongst particular target groups – how they can be used to deliver messages such as “accept we all live with HIV/AIDS”

7. Indicators to measure communication and stigma

- Number of times PLHA are depicted as victims, negative connotations
- Increase in number of times that AIDS is described sensitively and compassionately in the media.
- Number of reports in media on HIV/AIDS
- Interest in going for VCT as a result of communication (but may not have anything to do with communication)
- Qualitative coverage
- Human face of HIV/AIDS depicted
- Number of people attending where HIV openly debated, community meetings, training programmes,
- Number of editorials, features that specially address stigma
- Number of stigma-related interventions
- Community attitudes
- Community based programmes/ home care
- Measuring social norms/attitudes

Stigma, Methodological Research Issues and Indicators to Measure Stigma

Methods used in research on stigma

Shalini Bharat, Tata Institute

Bharat's presentation primarily centered on methods used in research on stigma. Some quantitative methods include surveys and scales and questionnaires (e.g. DHS, UNAIDS). Scales have been developed to measure attitudes toward the AIDS epidemic, people with HIV, specific groups of the population (e.g. prostitutes), and the etiology of AIDS (e.g. the belief that HIV is brought in by outsiders).

Qualitative methods can include in-depth interviews (as was used by Bharat in India and in Uganda) to explore:

- meanings associated with stigma,
- contexts & dynamics of stigma ,
- rationale behind stigma ,
- actual incidents of stigma,
- perceived stigma and fear of disclosure,
- self stigma and self image

The case study method can be employed to elicit personal testimonies of HIV infected and affected people over a period or in different settings. Focus group discussions are useful in exploring societal perceptions, underlying assumptions, and the cultural construction of stigma. Non participant observation can be used to record behaviours, events, or signs indicative of stigma (e.g. the use of observation schedules and checklists).

Within quantitative methods, Bharat noted a preponderance of self-reported measures in scales and questionnaires. They tend to explore how people would act in a hypothetical situation rather than examine actual behaviour. Most instruments are developed for use with the general population to assess how they feel toward people with HIV. Far fewer assess how people with HIV feel. She discussed using qualitative methods, such as focus groups, to develop survey instruments for quantitative research, and combining the methods in other ways.

Bharat suggested that the use of observation schedules/checklists would be helpful for observing labels and markers; the placement of PLHAs bed at home/in hospital; and the practice of using gloves, other infection control measures. Standardized observation instruments could be adapted.

She cautioned that a clinic-based study examines a non-representative sample and looks at stigma in only one domain. Stigma should be explored in other areas (e.g. household work). She encouraged investigation of those who experience multiple stigmas, either those among hard-to-reach populations or those that are already stigmatized because of age, gender, behaviour, etc. Bharat also suggested developing a gender perspective for instance, by examining stigma among women as caregivers and among pregnant women.

Bharat noted the need to distinguish between:

- Overt and covert stigma
- Enacted and felt stigma
- Societal and self stigma
- Stigma and discrimination

She commented that household members of people with HIV, children infected/affected by HIV/AIDS, and stigma among health providers/counsellors are all areas that have been neglected by current research. She also suggested having the community and people with HIV participate in the research design or perhaps as field interviewers.

Some indicators for measuring stigma may be:

- Percentage of people in a community going for VCT
- Percentage of people in a community attending AIDS awareness camps
- Percentage of people testing positive and disclosing status to various categories of people
- Percentage of people using AIDS hotline services
- Positive people joining support groups (by sex)
- Percentage of people with HIV who report they delay seeking care
- Percentage of people who seek care located far away
- Percentage of people who report self segregation of personal items

Bharat ended by discussing some ethical questions in research on stigma:

- Is participation in research a source of stigma?
- How does fear of disclosure, confidentiality, and written consent affect research?
- What about participation from people in the state of denial?
- Who are the intended beneficiaries of stigma research?
- Does research further stigmatize or does it sensitize others to the issue?

Working Group 6: Stigma,indicators and methodological issues

A 10 minute facilitator summary was presented based on the e-mail discussion forum and background documents

1. Main research priorities

- Identify indicators for global dimensions of stigma and methods for illiciting local dimensions of stigma
- Methods to understand underlying causes of stigma in Africa need to be explored and disseminated
- Methods that look at issues around disclosure and stigma in a family setting need to be explored (including checking longitudinal data)

2. Indicators to measure stigma

The group discussed global indicators and decided that generic indicators would be more appropriate. Examples of generic indicators:

- Engaging or not engaging in social activities
- Withdrawal from certain settings
- Delay in access
- Gender indicators e.g. MTCT interventions
- Access to legal support
- Litigation in courts
- Practices surrounding death

Local indicators are also important (e.g. exclusion from the ceremonial bath in death ritual in India). There also need to be different indicators for different levels (e.g. community, household, individual, defined groups, policy).

Stigma can be measured first by identifying the dimensions of stigma (a qualitative process) then by using instruments (scales, observation schedules and checklists, longitudinal studies, free listing).

3. Key methodological research issues

There is a need to combine generic and local indicators. Additionally, qualitative research is needed to understand stigma. This group expressed a need to capture the dynamics of stigma through longitudinal data and to capture a comparative perspective. Larger, quantitative studies may convince others.

Research should be designed around settings where interventions are needed (the emphasis here is on operational research, relevant variables, and how to intervene).

4. Ethical considerations

- Ethical encompassing: informed consent (genuine & involve education of rights); confidentiality; involvement of study population; not raise expectations falsely; concrete support to study population; linkages to services for study population (e.g. welfare, legal, counsellors)
- Key partners wide in design & feedback & transformation to intervention, but actual data collection & analysis involve a smaller group (this should include study population e.g. Using local researchers etc

Closing session

A play on AIDS stigma - "Wewe na Mimi"

The director introduced the play by explaining that many participants were concerned about the negative and depressing face of HIV/AIDS portrayed in the first act of the play. He calledfor audience participation at the end of today's performance. "If you were annoyed, we hit the mark. As artists, we take the license of exaggeration; otherwise we would just be the same as real life and that is boring. So, if you were annoyed, that was our purpose."

"Today, the play is short, but participatory. We request the audience to be attentive to the play and join at the end to see how the conflict in the play can be resolved. And have members of the audience to put themselves in the place of the various characters and see how they might resolve the situation…

The play was an exploration of some of the conflicts that may arise in the process of fighting against AIDS stigma. A lively and colourful stage set the scene for a local wedding. The bride's family believes that since their daughter is a virgin and is AIDS free. However, they demand that the bridegroom should be tested. He goes for a test and finds out he is HIV-positive. He conceals the information and proceeds with the wedding ceremony. Just as the couple are to be joined, the doctor runs on to the stage waving his test results. The scene is frozen and the audience are asked:

- Should the doctor who did the testing reveal the information or not?
- Was it right for the bride's side to decide not to test the bride?
- What do you think of the bridegroom's decision to conceal the information?

Following the play, there was an animated discussion among participants as to what should happen next. Several felt that the doctor should be allowed to break up the marriage ceremony, and the couple should not be allowed to be married, given the boy's silence, concealment and denial of his condition. Many participants felt that we needed to "break the silence". Still others felt that it was for the bridegroom to choose what to do. Others felt that it was the doctor's responsibility to offer proper counselling. One workable solution which was offered was that the wedding would proceed, but the young couple would agree to the use of condoms. Quickly, however, this option was not agreeable to the mother-in-law who indicated that she wanted grandchildren!

The Chairman closed the session and articulated the dilemma portrayed in the play by saying that "everyone should have the right to marry, and a married couple has the right to be safe…"

Cast:

Bride:	Neema Mirambo	Women:	Kise Bernard &
Bridegroom:	Haji Maeda		Elizabeth Buriani
Doctor:	Abrabam Bafadhili	Men:	Michael Kadinde &
Bar manager:	Elangwa Mtahiko		Issa Mtumbwe
Waitress:	Christa Komba	Joker:	Juma Bakari
Elder:	Allan Lugome	Technician:	Zackaria Ngulunda
		Directed by:	Juma Bakari

Closing Address

E.P.Y Muhondwa, Associate Professor, Institute Of Public Health, Tanzania

Stigma makes social interaction difficult. Suggesting (to one's partner) the use of condoms raises the suspicion of being infected. People don't want to raise suspicion. Stigma also leads to delays in seeking appropriate health care. Stigma leads to denial. Those who live with the consequences are not willing to speak out. So we live with the silence. It's not just politicians who don't speak out, but all members of society. Let's call for elimination of stigma. Call for everyone, not just some. Let's eliminate stigma. This conference was an important activity. We've looked at definitions and we've discussed indicators and operations research to help us do interventions in different settings. We are now calling on partners and governments for resources. Our governments need to provide resources. We need profiles of courageous people who have stood up and declared their status. What was it like for them? What were their feelings? Where did they get the energy? What stigma did they face? These case studies can teach us a lot. HIV and its effects will be with us a long time. One of the speakers painted a picture for us of a "Dys-functional" society as a consequence of stigma and HIV/AIDS.

In closing, participants paid tribute to Philly Bongole Lutaaya, the first public figure to live openly and positively withr HIV/AIDS in Uganda. The conference closed with everyone singing his song, Alone and Frightened, led by Noerine Kaleeba. Appropriately, the final song was "Unity: *In U-N-I-T-Y, we are all one."*

MEETING OUTPUTS

Technical Working Group

A working group of regional/global partners (WHO/AFRO; UNICEF/ESARO; ANNEA; Network of AIDS Researchers in Eastern and Southern Africa (NARESA); SANASO; Population Council, Family Health International; SWAA; Salvation Army; SIDA; HDN and UNAIDS) decided to form a Stigma Task Force, with UNAIDS Intercountry Team temporarily serving as the coordinator, in order to maintain the momentum on stigma.

The Task Force will attempt to ensure the following through the various members:

- Stigma advocacy and networking (ANNEA, SANASO);
- Operational research and resource mobilisation (NARESA, Population Council, FHI and others);
- Communication (SAfAIDS, PANOS);
- Ongoing stigma dialogue (HDN, Af-AIDS);
- Capacity building (NARESA and others); and
- Focus on priority areas, e.g WHO/AFRO on stigma and the health care sector; UNICEF/ESARO on stigma and children; etc.

Each organisation and their respective networks and members agreed to highlight the impact of HIV/AIDS stigma in their respective areas of work and advocate for stigma-reducing operational research and interventions/activities. In addition they agreed to build capacity and mobilise resources in order to conduct stigma-reducing operational research and interventions/activities.

It was proposed that the Task Force would prepare a joint proposal, reflecting the various components, requesting funds from various donors, including Swedish International Development Agency (SIDA), to ensure that initial funds are made available to continue the momentum on stigma reduction in the priority areas with some of the involved organisations.

Participants listed numerous regional programmes that can be mobilized to intensify their work on stigma and their own comparative advantages. In particular, several are already working on research on HIV-related stigma. The Task Force should look at all aspects of care and support issues, youth participation, and capacity building for people with HIV (how it can be made a reality). Participants reminded themselves that it will be important to include youth and people with HIV, not just as research subjects. Although research is broad (i.e. not limited to operations research), it should try to be participatory and action-oriented, not just academic. Resources need to be mobilized for the research agenda.

Advocacy for Action on Stigma and HIV/AIDS

A small working group generated an advocacy statement which was reviewed and agreed upon in plenary session. This statement was printed and disseminated at the United Nations General Assembly Special Session on HIV/AIDS (UNGASS) and will be available at other future conferences, as well as to be used at country, institution and individual levels. The statement is found in Annex 2.

Annex 1: List of reading materials available

All documents mentioned can be viewed and dowloaded at: http//:www.hdnet.org

1. **Meeting agenda and all presentations**
2. **List of participants**
3. **Meeting background documents**
   - Stigma-AIDS: Summary of electronic discussion forum
   - Review of issues and responses based on literature review, focus group discussions and Stigma-AIDS email discussion forum (draft)
4. **Meeting background information**

5. Background information

1. ANNEA addresses stigma in Tanzania
2. Association of an interest group concerned with the stigma associated with HIV/AIDS in Botswana.
3. Southern Africa Network of AIDS Service Organisations (SANASO)
4. Stigma and HIV/AIDS in Eritrea: potential UNAIDS operational research activities
5. Selection of stigma in the news in Africa
6. The concept behind the establishment of UMULA network
7. Strategies for working on the theme stigma, Panos Southern Africa AIDS Programme
7a. Working with policymakers and non-governmental organisations to promote understanding of and reduce the impact of HIV/AIDS related stigma.
8. Stigma - Children's experiences
8a. The role of Stigma and Discrimination in increasing the vulnerability of children & youth affected by HIV/AIDS
9. Outline of the DENOSA-SANNAM plan on Stigma and AIDS
10. Stigma and communication
11. Islamic Medical Association of Uganda
12. Tanga AIDS working group addresses stigma in Tanzania through inter-regional community exchange
13. Addressing HIV related stigma and discrimination, a collaborative project of the International Center for Research on Women, the CHANGE Project, and local partners
14. Stigmatisation of HIV/AIDS, 1999, Soul City Baseline Survey
15. Stigma and the media in Zimbabwe
16. Duduza Care Center addresses stigma in South Africa
17. The Disaster Management Information Project (DMIP) in Zimbabwe
18. Shedepha+ Tanzania, National Network of People Living with HIV/AIDS: A testimony on stigma and discrimination at the working place
19. Conceptual framework for “PLHA friendly” hospitals
20. Promoting Voluntary Counselling and Testing (VCT), National Aids Control Programme, Tanzania, March 2001
21. Alone and frightened, Song by Philly Bongole Lutaaya

6. HDN Key Correspondent daily reports from the consultation

Annex 2: Advocacy for Action on Stigma and HIV/AIDS in Africa

Regional Consultation Meeting on Stigma and HIV/AIDS in Africa
4 - 6 June 2001, Dar-es-Salaam

A meeting entitled "Stigma and HIV/AIDS in Africa: Setting the Operational Research Agenda" was convened in Dar-es-Salaam, Tanzania from 4-6 June 2001. It was attended by 80 participants representing organisations of people living with HIV/AIDS, physicians, nurses, researchers, communications specialists, community workers, faith-based organisations and UN agencies from 15 countries, primarily from Eastern and Southern Africa.

Context for Action

The participants of this regional consultation on stigma and HIV/AIDS in Africa recognise that, in one way or another, we are all living with or affected by the epidemic. We also recognise that stigma - characterised by silence, fear, discrimination and denial - fuels the spread of HIV/AIDS. It undermines prevention, care and support; it also increases the impact of the epidemic on individuals, families, communities and nations.
For these reasons, stigma must urgently be confronted. This paper describes the context in which stigma against persons with HIV/AIDS occurs, and makes recommendations for tackling it.

Stigma and discrimination

In the AIDS context, stigma is most simply defined as negative thoughts about a person or group based on a prejudiced position The "undesirable differences" and "spoiled identities" that HIV/AIDS-related stigma causes do not naturally exist, they are created by individuals and by communities. HIV/AIDS-related stigma builds upon and reinforces earlier prejudices. It plays into, and reinforces, existing social inequalities – especially those of gender, sexuality and race. HIV/AIDS related stigma also derives from HIV/AIDS' association with some of the most elemental parts of the human experience: sex, blood, disease and death. It is also associated with behaviours that may be illegal or forbidden by religious or traditional teachings, such as pre- and extra-marital sex, sex work, men having sex with men, and injecting drug use.

HIV related discrimination is action that results from stigma. It occurs when a distinction is made against a person that results in their being treated unfairly and unjustly on the basis of their actual or presumed HIV status or their belonging, or being perceived to belong, to a particular group. HIV-related stigma and discrimination is widespread. In Africa as in other parts of the world, such stigma results in rejection, denial, and discrediting, and consequently leads to discrimination which inevitably frequently leads to the violation of human rights – particularly those of women and children.

Leadership

Leaders at all levels- not just those in government but also religious and traditional leaders - have a clear responsibility to create a more open society that is free from stigma, silence or denial about the epidemic.
Modelling honest and open discussion about HIV/AIDS is a way leaders can strongly encourage supportive attitudes and responses to all those living with and affected by the

epidemic. In particular, they should acknowledge that they personally, as well as professionally, are living with and affected by the epidemic as anyone else in society. Experience from around the world shows that by discussing HIV/AIDS openly and sensitively and then taking action, leaders can make a difference.

People living with HIV/AIDS

The active involvement of persons living with or affected by HIV/AIDS is central to the fight against stigma. This is a crucial lesson learned in all countries that have succeeded in countering the epidemic. However, the responsibility is not theirs alone: all individuals and all sectors of society must accept the moral obligation to fight stigma and to promote openness, acceptance, and solidarity.

Human rights

Existing human rights instruments (notably international conventions, Treaties, Covenants and national legislation) confirm that discrimination against people living with HIV/AIDS, or those thought to be infected, is a violation of their human rights.
These instruments also provide an array of formal mechanisms to monitor and enforce HIV/AIDS related rights and rights of people living with HIV/AIDS, and to redress discrimination. However, in order to comprehensively address HIV/AIDS related stigma and discrimination, complementary strategies are required *within* homes and communities, health care settings, religious organisations and various communications media, both to prevent prejudicial thoughts being formed and to address or redress the situation when stigma leads to discriminatory action, negative consequences or denial of entitlements or services.
The following recommendations stem from recognition that such complementary strategies are needed, and propose practical means for implementing them.

Recommendations for action

Stigma and the family

Stigma within the family, or directed toward an affected family, is the most subtle and debilitating form of stigma and the hardest to address. By inhibiting open, honest communication, stigma makes disclosure within the family difficult; without disclosure, prevention and care is almost impossible. Families and communities - the two are deeply intertwined in the African context - should therefore be supported in preventing stigma, which will further enable their natural caring role. This will also promote self-esteem for people living with HIV/AIDS and their carers, and avoid vicious cycles of self-stigma.
The meeting prioritised the following key responses to stigma within families and communities:

- Conduct research on disclosure and stigma in the family setting, and use the findings design actions to promote openness and acceptance.
- Promote life-skills education and counselling to help HIV-infected and affected children cope with stigma.
- Ensure that an essential “package” of services including voluntary counselling and testing (VCT) and follow-up care are available: this will enable individuals to learn their serostatus and provide support for deciding whether to disclose their status to other family members.

- Raise awareness so that families and communities can access interventions (e.g., prevention of mother-to-child transmission, care and support services, etc.) as they become available, or hold authorities accountable if not available.

Stigma in health care settings

People working on the "frontlines" of HIV/AIDS care and prevention have both a responsibility and a unique opportunity to overcome stigma within their professions and workplaces. Their professional codes of ethics and conduct, social and professional authority, and their ability to act as educators and role models for their communities, all place them under an ethical obligation to be "change agents" for reducing stigma. Unfortunately experience shows that health care institutions and individuals sometimes perpetuate stigma by stigmatising and discriminating people, despite their professional codes. Further, health care workers who are (or are presumed to be) HIV-positive may suffer discrimination from colleagues and from their communities.
The meeting prioritised the following key responses in health care settings:

- Scale up provision of health services that are "friendly" to people living with HIV/AIDS, including VCT and care and support services.
- Develop discharge and referral systems that specifically avoid stigmatising patients.
- Ensure codes of ethics and professional conduct for health care services are in place and are enforced, offer sufficient forms of redress should violations of professional ethics occur, and that their application to HIV/AIDS is taught within professional training curricula.
- Encourage practical and attitudinal HIV-related training for all health care workers.
- Promote VCT and care and support for health care workers.
- Establish and provide adequate funding for comprehensive HIV/AIDS care within the existing health systems.

Stigma and the religious sector

The religious sector (churches, mosques, religious schools, lay groups, religious NGOs, ecumenical groups, etc.) have far-reaching influence throughout Africa and the rest of the world. They therefore have a responsibility to promote, prevention, and to provide care, comfort, and spiritual support to individuals and communities who are HIV-infected or affected. In particular, religious leaders must play an active role in disseminating non-stigmatising and discriminating preventive messages, and in leading the fight against stigma wherever it occurs.
The meeting prioritised the following key responses for the religious sector:

- Ensure religious leaders are "AIDS-competent" by including HIV/AIDS-related subjects, including counselling skills, in their pre- and in-service training.
- Integrate holistic care and support programmes in service and education activities, including life-skills for youth, home-based family care, support groups for infected and affected persons, and support for orphans.
- Identify religious language and doctrines that are stigmatising, and promote alternative language that is caring and non-judgmental.
- Promote humanitarian and spiritual values of compassion for marginalised and stigmatised groups.

Stigma and communications

While mass media – such as radio, TV, print, and the Internet. . - can unintentionally promote stigma, they can also serve as powerful tools to help reduce it. Given their potential to shape the attitudes, values and perceptions of large numbers of people,

communicators have a responsibility to create clear messages about HIVAIDS, to report accurately, and to do so in a sensitive, non-stigmatising manner.
The meeting prioritised the following key responses for mass media:

- Build skills and capacity for journalists, editors, producers, AIDS activists, communicators and people working in the field of HIV/AIDS.
- Provide resources for sustained communication about HIV/AIDS that effectively reduces stigma.
- Develop media standards for reporting on HIV/AIDS in a non-judgemental and non-stigmatising manner.
- Hold communicators (both individuals and their organizations) accountable for upholding the above standards through broad-based monitoring mechanisms developed on a country/regional basis.

Conclusion

Promoting hope and acceptance is a key response to stigma at all levels of society. In contrast, doing nothing about stigma can only contribute to the growing death toll, as well as to distress and reduced quality of life for millions of people.
All those with influence and authority within society have a responsibility, individually and collectively, to act in order to reduce stigma about HIV/AIDS within their spheres of influence. Accountability - based on transparency, honesty and openness – is a key component in improving HIV/AIDS prevention, care and support efforts, and to bring them to more people on an ongoing, sustainable basis. Clearly, it is essential that stigma and discrimination be monitored and redress be provided when discrimination occurs in all of the areas discussed in this paper.
While we may never fully eliminate stigma and discrimination, the recommendations contained in this paper will go a long way to reducing them, and to building the responsibility and accountability that is so desperately needed.

This publication is a production of the UNAIDS, Health & Development Networks (HDN) and the Swedish International Development Agency (SIDA). The content of this publication is drawn from a Regional Consultation Meeting on Stigma and HIV/AIDS in Africa from 4-6 June 2001. The views expressed, herein, are not necessarily a reflection of the above mentioned organizations.

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For more information about the Consultation or http://www.hdnet.org

November 2001

Annex 3: Meeting Agenda

Monday, 4 June - Issues and responses to stigma and AIDS

08.00 - 08.30	Registration	
	Opening Session	
08:30	Arrival of Guest of Honour	
08:40 – 08:50	Welcome address on behalf of UNAIDS	Dr W. Mwambazi, UN Theme Group on HIV/AIDS, Tanzania
08:50 – 09:00	Welcome address on behalf of Swedish International Development Agency (SIDA)	H. E. Mr S. Rylander Ambassador of Sweden
09:00 – 09:20	Opening address	Hon. F. T. Sumaye, Prime Minister
09:20 – 09:40	Keynote address	Mrs Noerine Kaleeba
09:40 – 10:15	Drama performance "Wewe na mimi – You and me"	Bagamoyo College of Arts

10:15 – 10:45 Tea/Coffee

Chair: Salvator Niyonzima

10:45 – 11:00	Introduction of participants Purpose and objectives of the consultation	Sandra Anderson
11:00 – 11:30	Links between stigma, discrimination and human rights	Miriam Maluwa/ Peter Aggleton
11:30 – 12:00	Overview of stigma: definition and context	David Miller
12:00 – 12:30	Stigma and HIV/AIDS in Africa: Review of issues and responses	Nadine France
12:30 – 13:00	Discussion	

13:30: – 14:00 Lunch

Chair: Emelia Timpo

14:00 – 14:20	Stigma and the health sector	Gloria Sangiwa

14:20 – 14:40	VCT in the context of stigma	Jessie Mwambo
14:40 – 15:00	Discussion	
15:00 – 15:20	Stigma and people with HIV/AIDS: self-stigma (unfortunately could not attend)	Frenk Guni Shuku
15:20 – 15:40	Stigma and people with HIV/AIDS: Peter Aggleton and societal stigma	Scovia K Nabagala
15:40 – 16:00	Discussion	
16:00 – 16:30	**Tea/Coffee**	

Chair: Jabu Makhanya

16:30 – 16:50	Stigma and the religious sector	Ian Campbell
16:50 – 17:10	Stigma, HIV/AIDS and religion in Namibia	Raphael Handler
17:10 – 17:40	Discussion	
19:00	**Cocktail reception, White Sands Hotel**	

Tuesday, 5 June: Operational research agenda and implementation plans

Chair: Kgoreletso Molosiwa

08:30 – 8:50	Stigma and communication	Felicity Hatendi
08:50 – 09:10	Stigma, children and youth: Soul City	Sue Goldstein
09:10 – 09:30	Discussion	
09:30 – 10:00	Stigma, methodological research issues and indicators to measure stigma	Shalini Bharat
10:00 – 10:20	Discussion	
10:20 – 10:30	Introduction to group work	Hilde Basstanie

10:30 – 11:00 Tea/Coffee

11:00 – 12:30 Group work

Group work: setting the research agenda for stigma-reducing and acceptance generating research/interventions

Topics	Group facilitators
Stigma and the health care sector	Elly Katabira/ Rose Maeda
Stigma and people living with HIV	Helen Ditsebe/Etambuyu Imasiku
Stigma and the religious sector	Ian Cambell/Sheikh Hassan Chizenga
Stigma and communication	Aulora Stally/Masimba Biriwasha
Defining and characteristing stigma	Mary Crewe/Peter Aggleton
Developing indicators for stigma	Eka Esu Williams/Shalini Bharat
Identifying methodological research issues	Henry Akinsola/Ginny Bond

12:30 – 13:30 Lunch

13:00 – 15:30 Group work continued

15:30 – 16:00 Tea/Coffee

Chair: Nadine France

16:00 – 17:30 Presentation of group work and discussion (10 mins presentation from each group and discussion)

17:30 – 18:30 Video showing

Open Secrets
Positive
Soul Buddies/Soul City
Tanzanian talk show DTV

Wednesday, 6 June: Way forward: research, advocacy and networking

Chair: Donna Kabatesi

08:30 – 08:50	Stigma, children and youth	Stefan Germann
08:50 – 09:10	Addressing stigma and disclosure in the workplace	Eka-Esu Williams
09:10 – 09:30	Discussion	
09:30 – 09:40	Introduction to group work	Hilde Basstanie
09:40 – 10:30	Group work	

Topics	Group facilitators
Health care workers	Jabu Makhanya/Evelyn Isaacs
PLWA, family, children	Lynette Thembi/Hores Isaacs Msacky
Religion	Karama Said/Dominique Mathiot
Media	Sue Goldstein/Bridget Sleap
Definition and indicators	David Miller/Koketso Rantona
Technical Working Group	Martina Smedberg/Jennifer Oyieke
Advocacy declaration	Major General Lupogo/Manju Chatani

10:30 – 11:00 Tea/Coffee

Chair: Sandra Anderson

10:30 – 12:00 Plenary: group work presentations and discussion

12:30 – 13:30 Lunch

13:30 – 15:00 **Closing session**

Chair: Fred Mhalu

Opening song:	Ross Kidd
Drama performance:	Bagamoyo College of Arts
Closing remarks:	Sandra Anderson, UNAIDS Martina Smedberg, SIDA Nadine France, HDN Florence Ngobeni, Baragwanath Hospital
Closing address:	Professo E. P. Y. Muhondwa, Deputy Chairperson National Advisory Board on AIDS
Closing song:	Noerine Kaleeba

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